

A Mixed Methods Investigation of the
Kansas Autism Waiver's Implementation:
The First Three Years

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ABSTRACT

This mixed methods study employed quantitative and qualitative methods as means of evaluating the Kansas Autism Waiver's first three years of implementation. The study was guided by the components of a quality assurance analysis and, to the extent possible, considered the fidelity of implementation of the waiver procedures. Data sources included child demographic variables, KAW service use variables, Vineland Adaptive Behavior Scale II (VABS II) standard scores, and the shared perceptions of parents, KAW service providers and management professionals. Findings included the existence of long waiting periods for children to be assessed for eligibility and to begin services once eligibility has been determined and a general underuse of all but one KAW service (i.e., Autism Specialist services). However, participants were primarily concerned with the intensive individual support service (IIS) and the need for more hours of intensive individual service providers. Numerous barriers to this service were identified, but the qualitative participants voiced no concerns about the sufficiency of the other services. Participants saw the coordination role of the Autism Specialist as very valuable and saw the required training offered by the waiver as useful and the function of the steering committee and support provided by the KAW program manager as important. The complexity of navigating the system and the need to better coordinate with other Developmental Disability waivers were also noted. The analyses of the VABS II standard scores as a measure of child outcomes were inconclusive and difficult to interpret and revealed scoring errors. The qualitative analysis also indicated concern with the present eligibility assessment and reevaluation system that relies on the VABS II Adaptive Behavior Composite standard scores. Despite the concerns raised, participants in the qualitative component of the study reported a number of positive child outcomes and expressed a high degree of satisfaction with the waiver. The implications of the results and recommendations for KAW procedures and policies are also offered.

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Chapter One

Introduction

Service provisions for individuals with developmental disabilities have historically been considered a “welfare” issue. In the first half of the 20th century, individuals with disabilities were typically “housed” in institutions (Snow, 2001). This “welfare” perception began to change with the advent of several historical movements.

In 1972, Geraldo Rivera’s televised raid of Willowbrook State School in the state of New York exposed the deplorable conditions that individuals with developmental disabilities living in institutional facilities had been experiencing for years and brought to light the lack of oversight and resources for such programs. Known as the Willowbrook scandal by many in the field of developmental disabilities, it was the subject of a book, *The Willowbrook Wars* (Rothman & Rothman, 1984).

The disability movement emerged, in part, as a result of this publicized raid. The Willowbrook exposé served to foster a growing interest in expanding community services that shifted away from institutional settings and played a significant role in documenting the need for quality oversight of programs delivered to individuals with developmental disabilities (Snow, 2001). During the same time period, Wolfensberger (1972) introduced the principle of normalization, which advanced the belief that disability is a normal part of life. It proposed that the lives of those with disabilities should be similar to that of other citizens in the community. The principle of normalization clearly indicated how societal perception of individuals with disabilities was changing.

The shift in perception applied to education as well as living situations. Public Law 94-142 was passed in 1975, mandating the education of children with disabilities in their local

school district. This was a significant turn of events in the lives of these children. A child with a disability was no longer viewed as someone to be warehoused in an institution, but seen as an individual deserving of an education. As the disability rights movement progressed, disability advocates promoted the importance of supports and services necessary to facilitate community living (Shumway, 1999). The passage of additional federal legislation specific to individuals with disabilities has continued to reflect changing societal views.

Congress enacted the Home and Community Based Services waiver program (Section 2176 of the Omnibus Budget Reconciliation Act of 1981) which was incorporated into the Social Security Act (the Act) at Section 1915(c). According to the Centers for Medicare and Medicaid Services (CMS) (LeBlanc, Tonner & Harrington, 2000), programs under the Home and Community Based Services (HCBS) waiver allow states to provide inclusive supports in the community for individuals eligible for Medicaid, including individuals with disabilities. The purpose of HCBS waivers is to provide the necessary services at a fraction of the cost of institutional care.

For the past 30 years, many states have focused on creating Medicaid HCBS alternatives to institutional care for individuals with disabilities (Kaiser Commission on Medicaid and the Uninsured, 2009). A state applies to the Centers for Medicare & Medicaid Services (CMS) for approval of a Home and Community Based Services waiver program. Once approved, a waiver allows the state to provide services to individuals who meet eligibility requirements while waiving some traditional requirements of Medicaid such as: parental income, care in the community versus in an institution, and the provision of specified non-medical services. As these Medicaid-funded services grew, program evaluation became a central issue. Almost two decades after the “Willowbrook scandal, Ray (1990) noted, in a

chapter addressing the role of the government in providing oversight for programs for persons with developmental disabilities, that service providers are still addressing the question of "what is quality and how to ensure it occurs" (p. 172).

Lakin and Prouty (2003) pointed out that, due to the rapid growth in community services associated with programs such as the HCBS waivers, states have not been able to keep up with the changing expectations regarding service quality or the tremendous variety in the service locations and providers. Additionally, they noted that, even when quality assurance measures were taken, numerous examples of flaws were still evident, including a continued emphasis on process versus outcomes.

Several highly publicized examples of services delivered in a substandard manner brought the issue of quality oversight to the forefront (Ray, 1990; Rothman, & Rothman, 1984). In fact, the focus on accountability in state services has increased since the 1990s when criticism regarding the oversight and effectiveness of government programs "became the foundation for efforts such as Performance Monitoring, Quality Management, Reengineering Government, Management by Objectives (MBO), Reinventing Government, and Managing for Results" (Patton, 2008, p. 22). This change in focus emphasized the need for more cohesive efforts at evaluation. In 2007 alone, the national percentage of Medicaid spending on HCBS more than doubled (Kaiser Commission on Medicaid and the Uninsured, 2009). As Medicaid HCBS Waivers expanded and spending increased, the importance of systematic assessment of program implementation increased in order to reduce costs and to improve the service delivery process and outcomes.

During the same period of time, one category of disability, autism, experienced a dramatic increase in prevalence (CDC, 2009). For decades, the prevalence of autism was

estimated to be 4 to 5 out of 10,000 children (1 out of every 2,000). The Centers for Disease Control (2012) recently published prevalence data that about 1 in 88 children has been identified with an autism spectrum disorder and ASDs are almost five times more common among boys (1 in 54) than among girls (1 in 252). There is uncertainty how much this increase in autism diagnosis is due to improved methods of identification and classification and how much reflects a true increase in the number of individuals with autism and related disorders. Regardless of the reason for the marked increase in prevalence, the need for appropriate interventions for individuals with autism has become increasingly urgent.

Ganz (2007) identified the per capita lifetime cost of autism at \$3.2 million. A study conducted in the United Kingdom by Jarbrink and Knapp (2001) estimated the costs of the lifelong care of an individual with autism and that the costs can be reduced by two-thirds with early diagnosis and intervention. Studies show that with intensive early intervention around fifty percent of children with autism can succeed in the regular education classroom by first grade (Jacobsen, Mulick, & Green, 1998; Granpeesheh, Tarbox, & Dixon, 2009; Lovaas, 1987; Sallows & Graupner, 2005, U.S. Dept. of Health and Human Services, 1999). Others will make gains significant enough that they will only require partial or less intensive special education services.

With the significant increase in individuals with autism over the past two decades and the accompanying recognition of the importance of interventions, a number of states have recently added waivers specifically for this population. Kansas is one of these states.

During 2006, Bryson and colleagues, members of the University of Kansas Social Welfare Department, interviewed Kansas's families and service providers within both the developmental disability and mental health fields (2008). The consensus was that the current

services available to individuals on the autism spectrum were not meeting the existing needs of Kansans.

In 2007, Kansas applied for the HCBS Waiver Program, the Kansas Autism Waiver (KAW), that according to the application, is designed to provide an “early intensive intervention that employs a waiver in order to have a greater impact on the lives of those children with ASD (Kansas Medicaid Waiver). Prior to the KAW, children with autism in Kansas were generally served through the MRDD waiver. This waiver was only available to children ages five and older. Thus, drawing from the available literature on evidenced-based practices (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Clark, Tuesday-Heathfield, Olympia, & Jenson, 2006; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Jacobsen et al., 1998; Lovaas, 1987; Sallows & Graupner, 2005; Smith, Groen, & Wynn, 2000), the Kansas Autism Waiver chose to serve children who enter the program prior to age six, employ an applied behavior analysis early intervention model, and provide limited services up to a maximum of three years unless it is medically necessary to serve a child for an additional year.

The Kansas application was approved in 2008 and implementation began that year. The waiver services were initially to be offered to 25 children and their families across the state who would receive consultative and clinical therapeutic services of an Autism Specialist, intensive individual supports, respite care, parent support and training, and family adjustment counseling. The waiver services have presently grown to serving a total of 45 children.

With this new waiver comes an increased emphasis on the need for systematic evaluation. The Kansas Autism Waiver has a stated purpose to produce outcomes, and, therefore, is essential to evaluate the achievement of those outcomes. Approaching a new endeavor systematically is

essential to effectiveness. Implementation takes place on multiple levels and so should evaluation.

During the period in which it has been provided, the KAW has gone through three stages of implementation as defined by Fixsen, Naoom, Blasé, Friedman, and Wallace (2005). According to Fixsen and his colleagues, the three stages include paper implementation, process implementation, and performance implementation (2005, p. 6). The first stage, paper implementation, involves putting into place the policies and procedures that guide the program. The second stage, process implementation includes establishing the procedural framework necessary to guide the program. This involves activities such as training, oversight, and monitoring systems. The final stage, performance implementation, focuses on the effect of services provided on intended consumers. In the last stage procedures and processes are implemented effectively and have a positive impact on consumers. Effective evaluation of a program implementation requires a review of the each of these processes and the outcomes of tasks associated with all three stages.

Purpose of the Study

The purpose of this dissertation research was to conduct a mixed methods design to: (a) examine the current implementation status of the Kansas Autism Waiver and the perspectives of multiple stakeholders and (b) identify policy and procedural recommendations for the Kansas Autism Waiver based on the results of the study. Six research questions were posed to guide the methodology and data analyses, as follows.

1. What do child demographic variables indicate about the characteristics of the children selected for participation in the KAW?

2. What does the use of the KAW services by the children and families indicate about its implementation?
3. Do the children's Adaptive Behavior Composite standard scores change from the initial and repeated administration of the Vineland Adaptive Behavior Scale II and, if so, what is the direction and degree of change?
4. Is there a relationship between changes in Vineland Adaptive Behavior Scale II annual scores of the children served on the Kansas Autism Waiver and the number of hours KAW services provided?
5. What factors do parents and professionals perceive as impacting the implementation of the Kansas Autism Waiver (KAW)?
6. What are the perceptions of parents and professionals regarding the outcomes for recipients of the Kansas Autism Waiver?

Organization of the Dissertation

The remaining chapters will be organized as follows: Chapter 2 includes a review of the literature, Chapter 3 describes study methods, Chapter 4 presents the findings from the quantitative data, Chapter 5 presents the findings from the qualitative data, and Chapter 6 discusses the implications of the findings as well as offers policy and procedural recommendations for the Kansas Autism Waiver.

Chapter 2

Review of Literature

This chapter reviews literature in areas foundational to an understanding of this study's purpose, methods and results. These include: (a) an overview of the diagnosis of autism, (b) a summary of interventions that primarily employ applied behavior analysis and occur prior to age six, (c) an explanation of the Medicaid waiver, (d) an overview of the development and major features of the Kansas Autism Waiver (KAW), (e) the components of and considerations for quality assurance analyses and documentation of program implementation, and (f) a brief review of studies that report about the implementation and/or outcomes of waiver programs.

Autism Spectrum Disorder

Autism Spectrum Disorders (ASD) is a term that is typically used to describe three of the disorders that fall under the category of Pervasive Developmental Disorder (DSM IVTR, American Psychiatric Association, 2000). They are called spectrum disorders due to the wide symptom range and severity and include autistic disorder, pervasive developmental disorder not otherwise specified (PDD NOS), and Asperger syndrome. For the remainder of this discussion, the term autism spectrum disorder (ASD) and autism will be used interchangeably to represent these three disorders. Autism is characterized by challenges in the areas of socialization, communication and atypical behaviors or interests. It is considered a developmental disability because it is a severe, often lifelong disability that affects individuals before they reach age 22 and substantially limits functioning ability in three or more life activities such as self-care, receptive and expressive language, learning, mobility, self-direction, independent living, and employability (Developmental Disabilities Assistance and Bill of Rights Act, 2000).

Autism prevalence estimates. According to 2008 estimates obtained by the Center for Disease Control and Prevention's, Autism and Developmental Disabilities Monitoring (ADDM) Network: (a) ASDs affects children and families of all racial, ethnic and socioeconomic backgrounds; (b) about 1 in 88 children has been identified with an autism spectrum disorder; and (c) ASDs are almost 5 times more common among boys (1 in 54) than among girls (1 in 252) (CDC, 2012). Moreover, the prevalence of autism has dramatically increased over the past two decades. The current estimate (i.e. 1 in 88 children) can be contrasted with 2001 estimates of 2 to 6 children per 1,000 (CDC, 2007).

Autism Speaks, the nation's largest autism advocacy organization, points out in their web site that more children will be diagnosed with autism this year than AIDS, diabetes and cancer combined (*Facts about Autism, Did you know* column). This increase in diagnosis may be occurring for many reasons, but the one thing that is agreed upon is that more children are being diagnosed.

Behavioral treatment of autism. Treatments for children with ASD range from biomedical to clinical and behavioral interventions (National Research Council, 2001) with “new” treatments frequently appearing. Considerable research conducted over the past 50 years has established strong empirical support for intensive early intervention for children with ASD that employs behavioral techniques (Granpeesheh et al., 2009; U.S. Dept. of Health and Human Services, 1999) and it is this research that guided many of the procedures included in the Kansas Home and Community Based Autism Waiver (KAW). Thus, it will be briefly reviewed here.

Techniques associated with applied behavior analysis (ABA) consistently result in most children with ASD making gains (Ingersoll & Schreibman, 2006; Smith, Groen, & Winn, 2000). Recent comparison studies of children receiving intensive behavioral intervention to children in

more eclectic programs have found that the children receiving behavioral treatment showed more gains in cognition, language, and adaptive functioning after approximately one year (Eikeseth, Smith, Jahr & Eldevik, 2002; Howard et al., 2005).

Early intervention. Intervention studies also indicate that early intensive intervention for these children is the most effective method for increasing functional skills, replacing challenging behavior, and improving quality of life (U.S. Dept. of Health and Human Services, 1999; Lovaas, 1987). Services provided to children during early childhood have the additional benefit of preparing children for entering the school system. Studies show that, with intensive early intervention, around fifty percent of children with autism can succeed in the regular education classroom by first grade (Jacobsen et al., 1998; Lovaas, 1987; Sallows & Graupner, 2005). Others will make gains sufficient to ensure that they will need less intensive special education service than might have been expected.

Characteristics that comprise effective early intervention services employing applied behavior analysis (ABA) include intensity, duration, and timing. Evidence suggests that intensive behavior analytic intervention from 15 (minimum) to 30 hours a week is most effective at producing long-term improvements in functional capacity for young children (Anderson, et al., 1987; Howard et al., 2005; Clark et al., 2006; Lovaas, 1987; Lovaas & Smith, 2003; Sallows & Graupner, 2005; Smith et al., 2000). In regard to the duration of services, the recommended time in treatment has ranged from one to more than four years of intense treatment (Ramey & Ramey, 1998). Most studies indicate that at least two years of intervention are needed to obtain optimal results (Green, 1996). Timing of intervention is also critical, with studies generally indicating that intervention should begin as early as possible, preferably before four years of age, for the

greatest potential impact (Bibby, Eikeseth, Mudford, & Reeves, 2002; Harris & Handleman, 2000).

Comprehensive reviews of interventions. The identification and implementation of evidence-based interventions and outcome measures through comprehensive reviews of intervention studies that address ASD have recently become a focus across professional organizations and agencies associated with human services. The May Institute is a private, nonprofit organization that provides educational, rehabilitative, and behavioral healthcare services to individuals with autism spectrum disorders and other developmental disabilities, brain injury, mental illness, and behavioral health needs. In 2009, the National Autism Center, which is the May Institute's Center for the Promotion of Evidence-based Practice, published the National Standards Report, which revealed their National Standards Project results. These results were directed to identifying treatments to ASD that have a scientific evidence base. Specifically, the National Standards Project undertook a comprehensive review of 775 research studies, published between 1957 and 2007, of specific types of intervention approaches applied to children and youth with autism. Eleven approaches met the project's criteria of an "Established Treatment", which is one that produces beneficial outcomes and is effective for individuals (under 22) on the autism spectrum. The majority of the 11 approaches were developed exclusively from the behavioral literature (e.g., applied behavior analysis, behavioral psychology, and positive behavioral supports) and include the following approaches to treatment: Antecedent Package (99 studies), Behavioral Package (231 studies), Comprehensive Behavioral Treatment for Young Children (22 studies), Joint Attention Intervention (6 studies), Modeling (50 studies), Naturalistic Teaching Strategies (32 studies), Peer Training Package (33 studies),

Pivotal Response Treatment (14 studies), Schedules (12 studies), Self-management (21 studies) and Story-based Intervention Package (21 studies).

Medicaid HCBS Waivers

The Centers for Medicare and Medicaid Services (CMS) is a federal agency within the Health and Human Services Department that administers Medicare and Medicaid, as well as other health related services within states. CMS partners with states to administer Medicaid programs. An HCBS waiver is a Medicaid service that a state can choose to provide for specific populations, and “waives” certain requirements for Medicaid eligibility (CMS, 2011).

In order to provide a HCBS waiver service to its constituents, a state applies to CMS. This federal agency must provide approval prior to the implementation of a waiver program. These provisions and the waiving of certain eligibility requirements allow the development of a set of supportive services to be provided to target individuals.

In many states, children on the autism spectrum have traditionally been served through a developmental disability waiver rather than one directed specifically to a diagnosis of autism, but this is beginning to change. Although many states serve people with ASD under their primary HCBS waiver, not all states explicitly included ASD as a specific related-conditions clause. Data collected during the 2009 to 2010 period revealed that, 33 states and the District of Columbia listed autism as a related clause or explicitly included autism in the definition of people served under the states’ HCBS waiver for people with intellectual disabilities. At the time these data were collected, 11 states offered autism-specific waivers for children and two had HCBS waivers for adults with autism.

The Kansas Autism Waiver (KAW)

The increase in prevalence, the federal identification of autism agendas, and intensive professional and parental advocacy for awareness of the often devastating affects that a child with autism has on families prompted professionals in the Kansas to advocate for the creation of a funding stream directed to the target population defined as “a young child with autism.” The Kansas Autism Waiver (KAW) was conceived and designed to provide early intensive intervention opportunities for children with autism with a goal of benefiting them and potentially providing a cost savings to the state. It was intended to fill service gaps within the existing system through the provision of home and community based services that would assist in keeping children out of residential settings by providing services that enhance skills in the areas of social independence, communication and behaviour (CMS, 2011).

A first step taken by the Kansas Department of Social and Rehabilitation Services (SRS) was to conduct focus groups that were held in different locations across the state comprised of stakeholders to assist in the development of the Kansas Autism Waiver. Stakeholders included parents of children with autism, providers within the field of developmental disabilities, faculty from Institutes of Higher Education, as well as state level policy makers. General recommendations were gathered from these initial focus groups. Numerous additional meetings were held in Topeka to discuss further refinement of these recommendations. These groups were comprised of similar stakeholders.

Next, Social and Rehabilitation Services identified a work group of 15 participants to develop the waiver application. The designations and service provisions for the waiver were developed via a consensus-based process among the stakeholder work group and are as follows:

- Young children will be able to enter the waiver program from the age of diagnosis through the age of five.
- A child will be eligible to receive waiver services for a time period of three years.
- The institutional alternative for the waiver program shall be a State Mental Health Hospital.
- Children who are determined eligible for the autism waiver can access services in the following areas according to their needs: respite care, parent support and training, intensive individual supports for up to 25 hours per week, consultative clinical and therapeutic services, and/or family adjustment counseling.

KAW service provisions. The Kansas Autism Waiver was developed to provide needed services to help fill the existing service gaps identified by participants in the statewide family forums, members of the Governor's Commission on Autism and the above mentioned stakeholder groups. Services provided through SRS within the Kansas Autism Waiver Program may enhance, but not duplicate, the services already mandated such the educational services provided through Part B and C of IDEA 2004.

Each family of a KAW recipient (i.e. child with autism) receives the consultative and clinical therapeutic services of an Autism Specialist (AS). If requested, additional services include intensive individual support services in their home and in the community (with the exception of school-based services), respite care, parent support and training, and family adjustment counseling. At a minimum, one of the optional services must be utilized each month. The following includes a brief explanation of these five services, as well as the service provider qualifications for each.

Consultative and clinical therapeutic services. Consultative clinical and therapeutic services (CCTS) are provided by an Autism Specialist and can be provided for up to 50 hours per year. These services are designed to assist in the implementation of the child's Individual Behavior Plan (IBP) and Plan Of Care (POC). The Autism Specialist provides one-to-one training to other KAW support providers, as well to as the family on implementation IBP and POC. An example of this might be providing modeling and coaching on how to implement a communication system within the child's daily routines. The Autism Specialist services is the only service that may exceed the maximum number of hours provided prior approval is requested and approved. An Autism Specialist is required to have a master's degree in a field related to education, psychology, or other social service and a minimum of 2,000 hours of experience working with individuals with autism. However, 1,000 hours of experience are waived if the provider is a Board Certified Behavior Analyst (BCBA).

Intensive individual support (IIS) services. Intensive individual support (IIS) services are provided by individuals who can assist in the implementation of the goals of the IBP/POC. If services are provided in a school setting, the services must not be academic in nature. This involves the implementation of evidence-based services with the child in their home and/or community setting and the collection of data on the child's performance. The data can then be shared with the Autism Specialist at the next visit or during a team meeting. A total of 25 hours of intensive individual support services can be provided each week of the year. An intensive individual support service provider must hold a bachelor's degree or a minimum of 60 hours of college credit and 1,000 hours of experience working with individuals with autism.

Respite care services. Respite care is intended to provide supervision for the child with autism and to provide a break for the parent or guardian. Parents of children with disabilities are

historically at a disadvantage when it comes to identifying care for their children and at a heightened risk of stress. Respite care is designed to provide a brief break from the everyday challenges of raising a child with autism. A total of 168 hours of respite care services can be provided each year and can be provided by an individual who is at least 18 years of age and has a high school diploma or its equivalent.

Parent support and training services. Parent support and training services are intended to provide information and support to parents about the unique needs of children with autism. They are intended to facilitate the parent's engagement in the intervention process and can be provided for a total of 30 hours of each year. Parent support and training services are provided by another parent of a child with autism or by a professional who is at least 21 years of age, has a high school diploma or the equivalent, and has three years of working experience with children with autism or has a child with autism three years of age or older.

Family adjustment counseling services. Family adjustment counseling services are individual counseling sessions provided by a Licensed Mental Health Professional. These services are intended to provide the family with the coping skills necessary to deal with the stress of having a child with a disability. A total of 12 hours of services can be provided each year.

KAW family procedures. The Kaw has a number of procedure or processes that are required of the parents or guardians of children who are selected for the waiver. These include procedures associated with: (a) applying for the waiver, (b) the determination of their child's eligibility, (c) the development of an Individual Behavior Plan and Plan of Care and (d) the selection of the services available through the waiver.

Application to the KAW. Parents or guardians must apply to SRS for their child to be placed on the proposed waiver recipient list if the child has a verified clinical diagnosis of an

Autism Spectrum Disorders (CDC, 2007), which includes Autistic Disorder, Pervasive Developmental Disorder, Not Otherwise Specified, or Asperger Syndrome. A child must be selected for the waiver before they are six years of age. Therefore, children can remain on the proposed waiver recipient list until they are selected prior to age six or until they turn 6 years old.

Participation in the assessment for eligibility. If a space on the waiver becomes available, the family or guardian of the child at the top of the list, in order of the application submission date, is contacted. If they remain interested, their name is passed on to a Functional Eligibility Specialist (FES) who initially administers the functional eligibility screening to determine whether the child still meets criteria for the application for services through the waiver. The FES then schedules a time with the family to come to their home to conduct the Vineland Adaptive Behavior Scale II assessment using the interview survey tool. This assessment is given to determine initial eligibility and re-administered annually to determine continued eligibility for the waiver. A child is determined eligible for the waiver based on several outcome scores on the Vineland II as follows:

1. If the child receives a total score or a score on any two elements of the Adaptive areas (Communication, Daily Living Skills, Socialization, and Motor Skills) of two standard deviations below the mean (score of 70) he or she is eligible for the Waiver or,
2. If the child receives a total score or a score on any two subdomains in the Adaptive areas (Communication, Daily Living Skills, Socialization, and Motor skills) at or lower than one standard deviation below the mean (score of 85), but above two standard deviations below the mean, the assessor then reviews the scores on the Maladaptive Behaviors Scale (internalizing score, externalizing score, or total score).

3. If the Maladaptive Score on the internal, external or total score is clinically significant (when compared to the Vineland II norm sample), the child is eligible for the Waiver” (Kansas Medicaid Application).

Participation in the IBP and POC and the identification of services. If a child is determined eligible, the parents or caregiver complete the necessary paperwork and the individual who will serve as their Autism Specialist is identified. The Autism Specialist then initiates consultative and clinical therapeutic services designed to provide the family and providers with the supports necessary for them to access evidence-based home and community services. These services include assessing the child and family’s needs, developing in collaboration with the family an individual plan of care that designates the frequency and focus of the individual services, determining the needed training and oversight for the delivery of the individual services.

KAW provider procedures. The individuals who provide the various services offered in the KAW must also follow specified procedures. Key procedures that are briefly described here include those associated with the assessment of the child’s needs, the development of an IBP and POC, the implementation of the IBP/POC determined services and participation in state approved training.

Assessment of child needs. The Autism Specialist must complete a criterion-referenced assessment of skill to determine the child’s needs. A commonly used tool is the *Assessment of Basic Language and Learning Skills – Revised: An assessment, curriculum guide, and skills tracking system for children with Autism or other Developmental Disabilities* that was developed by James Partington (2008). The *ABLLS-R* is designed to assist in identifying deficiencies in language, academic, self-help, and motor skills, as well as in the implementation and monitoring

of individualized intervention. The results of this assessment are used to begin the development of the Individual Behavior Program and a Plan Of Care (IBP/POC) for the child.

Development of an IBP/POC. Following the criterion referenced assessment, the Autism Specialist develops, in collaboration with the family, an Individual Behavior Program and Plan Of Care (IBP/POC) for the child. This IBP/POC is considered the basis for determining the services the child will receive through the waiver. The IBP/POC includes an overview of the child's needs, as well as the family's priorities and support needs and services within 12 domains as follows: behavior; expressive, nonverbal, and receptive communication; community readiness skills; concept formation skills; family environment; imitation and attending; leisure, recreation and play; motor skills; self-help skills; and social interactions.

Implementation of IBP/POC determined services. The intensive individual support (IIS) services required by the individual behavior plan are implemented by an IIS provider who is assigned to work directly with the child in the home and/or community and to document the child's progress in the 12 domains.

Participation in state approved training. Each individual who provides services to a child and family as part of the waiver is required to complete a state approved training in order to bill for their services. The training is currently provided through the Kansas Center for Autism Research and Training. An individual must complete the training within six months of being selected to serve as a provider.

The specific content and format of the training varies depending on the role of the individual providing services within the waiver. Autism Specialists complete both online training and two days of onsite training, which includes both clinic based and on-the-job training. Intensive individual support providers (IIS) complete an online training and six days of onsite

training, which includes a lecture component as well as individual practice with children with autism in clinical settings and in the child's natural environment. Both the respite-care providers and the individuals providing parent support and training complete the online portion and attend a three-hour workshop.

Quality Assurance

The definition of the term *quality assurance* set forth by Harman (1998) in a review of international practices associated with the oversight and documentation of quality in public programs pertains to this discussion. Specifically, he defines quality assurance as, “the systematic management and assessment procedures adopted to ensure achievement of specified quality or improved quality, and to enable key stakeholders to have confidence in the management of quality and the outcomes achieved” (p. 346).

The principal managed-health care trade associations joined together to form the NCQA (National Committee for Quality Assurance) in 1979 (Iglehart, 1996) with a goal of articulating practices that bridged the gap between professional judgment and objective standards. Despite the efforts of the NCQA, Iglehart reported that attempts up to the point of the mid-1990s to determine the quality of program implementation associated with health care delivery primarily involved subjective professional judgment.

Quality assurance of Medicaid programs. On March 19, 1993, the U.S. House of Representatives conducted a hearing that examined the quality of community services for persons with developmental disabilities and concluded that, “State public officials charged with their oversight had little or no knowledge of the conditions within their homes . . . or at best found out only after terrible events had occurred” (Lakin & Prouty, 2003, p.10).

According to an article addressing problems with providing Medicaid managed care for persons with developmental disabilities, Ronder, Kastner, Parker, and Walsh (1999) reported that the most significant problems were waiting lists, limited access to services and a lack of quality assurance. These authors noted that, “There are only a few models of comprehensive quality management and outcome evaluation programs for people with developmental disabilities nationally” (p. 25).

The President’s Committee on Mental Retardation (PCMR, 1999), now referred to as the President’s Committee for People with Intellectual Disabilities, issued a booklet in 1999 to address quality assurance. The booklet set forth the committee’s discussion of the changing definition of quality, which pointed to a de-emphasis on compliance and process issues and an increased focus on how programs affect the lives of the people they serve. According to Lakin and Prouty (2003), what was viewed as quality in community services in 1982, or even 1992, no longer met contemporary values. They asserted that in addition to the protection of health and safety, definitions of quality in human services must address dimensions associated with quality of life. The PCMR 1999 booklet noted that:

- Quality is increasingly being measured by the achievement of personal outcomes, which are important to the individual.
- Emerging quality assurance programs are beginning to emphasize providing for the highest possible quality of life. This new way of looking at quality considers what the person wants and needs holistically and it recognizes that the measures of quality of life are the same for people with disabilities as they are for everyone else.
- Emphasis is being placed on providers “owning” their own internal quality improvement programs rather than having the definition and reinforcement of quality being imposed by

the outside. Service providers are beginning to develop or adapt their own standards, monitor their own progress, and develop mechanisms for continuing quality improvement (p. 5).

At a more practical level, the PCMR also suggested that some things that quality assurance systems can measure are the following:

1. *Inputs.* Inputs may be such things as the number of staff provided, or the number of hours of staff training. Traditional quality assurance is heavily concerned with inputs.
2. *Process.* Traditional quality assurance also monitors compliance with regulations that prescribe exactly how a service is to be delivered. Some examples are: required daily logging of consumer's activities and moods or cleaning the kitchen counters with bleach solution twice a day.
3. *Impact.* Impact refers to the effect on the greater society. An example might be the effect on the community work force, such as supplying hard-to-find labor, and providing stable, long-term employees.
4. *Reactions of participants.* This might refer to their satisfaction with the program, staff, home, etc., or what they liked most or least about the services.
5. *Organizational effectiveness.* Quality measurement can also relate to the activities of an organization in such areas as having a mission, appropriate policies, sufficient human resources, and demonstrating fiscal responsibility.
6. *Data profiles created by Management Information Systems.* These are computer-based systems intended to provide an ongoing database to improve the quality of organizational structures or information that facilitates system-wide decision-making.
7. *Quality of life.* The concept of quality of life is rapidly becoming the assumed desired

result of good services. Quality of life is difficult to define for others. Yet it is what most outcome models of quality assurance assess.

8. *Outcomes.* Outcomes-based documentation systems are now considered essential in most of the newer quality assurance programs. In the context of services and supports for people with developmental disabilities, outcomes are defined as changes in adaptive behavior(s) and role status that are logical consequences of the (re)habilitation service(s) (Schalock, 1995), or the way in which the program influenced the participants and the community (p. 12).

Special Needs Plans (SNPs) were created by Congress in the Medicare Modernization Act (MMA) of 2003 as a new type of Medicare managed care plan focused on “certain vulnerable groups of Medicare beneficiaries” including individuals with developmental disabilities. According to Lakin and Prouty (2003), due to the rapid growth in community services associated with programs such as the HCBS waivers, states had not been able to keep up with either the changing expectations regarding quality or the tremendous variety in locations and providers. They also noted that when quality assurance measures had been taken, there were numerous examples of flaws including a continued emphasis on the process involved rather than actual outcomes.

In response to numerous inquiries from state Medicaid programs, the National Committee for Quality Assurance created its first Medicaid Managed Care Toolkit in consultation with the Centers for Medicaid and State Operations in 2006. In early 2008, the Centers for Medicare and Medicaid Services (CMS) contracted with the NCQA to develop a strategy to evaluate the quality of care provided by the Special Needs Plans (SNPs). This strategy employs a phased approach that begins with defining and then assessing desirable structural characteristics. This is

subsequently followed by the assessment of processes and, eventually, outcomes. Beginning in 2012, the NCQA is focusing on evidence of implementation of policies, procedures, processes and programs and use of systems.

Implementation Fidelity. Implementing program components exactly as designed is called implementation fidelity and is essential to quality assurance (Gresham, MacMillan, Beebe-Frankenberger, & Bocian, 2000). Implementation of programs such as the Medicaid waiver programs occurs on many levels, and, therefore, the evaluation of implementation should also take place on multiple levels. As stated by Osborne and Gaebler, (1992) in their book *Re-inventing Government*:

- “What gets measured gets done
- If you don’t measure results, you can’t tell success from failure
- If you can’t see success, you can’t reward it
- If you can’t reward success, you’re probably rewarding failure
- If you can’t see success, you can’t learn from it
- If you can’t recognize failure, you can’t correct it.
- If you can demonstrate results, you can win public support” (p. 146-155).

Research that examines the fidelity of implementation of the program components is a fairly new science. The mission of NIRN is to help bring research to practice and impact communities and individuals. Fixsen and his colleagues have explained that the systemic factors that provide the context in program implemented must be understood (Fixsen et al., 2005). Thus, when reviewing implementation of a new program, it is important to understand the implementation context, which include factors within the implementation, as well as external factors that affect the implementation at a system level.

The importance of the assessing the fidelity of implementation across three stages or levels of implementation was also articulated by Fixsen and his colleagues (Fixsen et al., 2005). These stages that were mentioned earlier in the introduction include paper implementation, process implementation, and performance implementation. The first stage, paper implementation, is the development of policies and procedures that guide the implementation of the program. The second stage, process implementation, is the development of the framework necessary to implement the program and include activities such as training, oversight and monitoring systems for the new program. The third and final stage, performance implementation is the actual delivery of services to the intended consumers. Without performance implementation, true change for the consumers is much less likely to occur.

Discussions of implementation fidelity commonly include the assessment of five components associated with the processes of implementation: adherence, dosage, quality of program/intervention delivery, participant responsiveness, and program differentiation (Dane & Schneider, 1998; Dusenbury, Brannigan, Falco, & Hansen, 2003; Knoche, Sheridan, Edwards, & Osborne, 2010; O'Donnell, 2008). *Adherence* involves assessing whether the intervention strategies are implemented as designed by program developers, including the training of staff persons. *Dosage/exposure* is assessing the amount of intervention that is delivered to participants, such as the duration and frequency of sessions. The *quality of program delivery* is different than just adherence and involves the assessment of quality with which intervention strategies are delivered, such as delivery with enthusiasm. *Participant responsiveness* is the assessment of the participants' level of engagement in the treatment, such as the degree of enthusiasm displayed by the participants. Finally, *program differentiation* is the assessment of

whether the intervention components were delivered cleanly. For example assessing whether the intervention group and the control group received different treatments.

Five hundred quantitative studies were reviewed by Durlak and DuPre (2008) with the purpose of assessing the impact of implementation on program outcomes and identifying factors affecting the implementation process. These researchers found that carefully implemented programs that were concerned with fidelity of implementation resulted in outcomes between two to three times better. Variability in intervention outcomes can often be attributed to variability in the fidelity of implementation efforts (Odom et al., 2010; Rossi & Freeman, 1985; Wolery & Garfinkle, 2002). Implementation variation affects outcomes at the system level (Fixsen et al., 2005; Odom et al., 2010; Patton, 2008), as well as the individual level (Bryson, Corrigan, McDonald, & Holmes, 2008; Symes, Remington, Brown, & Hastings, 2006). Interpreting the effectiveness of interventions without also measuring fidelity of implementation may lead to false conclusions.

Data Based Investigations of HCBS Waiver Programs

Information about the effectiveness of the Medicaid Home and Community Based Services (HCBS) in contributing to the health, well being, and quality of life of HCBS recipients has been limited or incomplete, particularly since the first community based waiver program was established in 1981. Studies that report data or pertain directly to the collection of data associated with the HCBS waiver programs are briefly reviewed in this section.

Laudicina and Burwell (1988) conducted a national survey of each of the waiver programs in all the states that had waivers at the time of the study. A total of 72 surveys were sent to 42 states. The survey was designed to capture two different types of data: the cumulative experience of each waiver program from its inception in October 1984 through September 1985,

and the key characteristics of each approved program during the selected study year.

Information was collected about the service population, waiver eligibility, waiver administration, screening and assessment, client characteristics, service utilization and cost issues, the role of the case manager and the quality assurance system in place. Results reported the impact of service utilization, case management, and the cost and roles of providers. These authors noted that although “two-thirds of the states performed an independent review of whether individuals received the services only one-third actually observed the individual or assessed outcomes” (p. 536, 1988). Independent quality review activities were most frequently performed annually. Interestingly, states reported more intense monitoring of waiver clients than that typically provided for the Medicaid population at large.

LeBlanc, Tonner and Harrington (2000) conducted a study of program implementation and quality assurance in all 50 states. Telephone interviews were conducted to each state’s Medicaid office to identify the appropriate person to interview. Data were collected in all 50 states and Washington DC between the fall 1998 and summer 1999. A structured interview protocol was used and the interview lasted an average of 42 minutes. Questions addressed eligibility criteria for the waiver or waivers, limits placed on the waivers in terms of costs and hours of service as well as about case management procedures provided and programs for monitoring client satisfaction and quality.

The results of the LeBlanc and colleagues (2000) study showed that only the state of Oregon funded larger numbers of participants in the home and community than in nursing homes or ICF-MR facilities. This relationship was reversed for all other states and Washington D.C.. States varied in their administrative structures. The average number of agencies utilized to administer their Medicaid services was slightly greater than two agencies, with seven states using

four or more agencies. Cost caps at both the individual and the aggregate level were implemented in most states and some states, including Kansas, imposed hour limits on services provided per day, per week, or per month.

Sixty-seven percent of the states reported that they had some measurement of client satisfaction, but the authors noted that this type of assessment was (a) left to the provider agencies, (b) were very limited, and (c) generally not incorporated across the program or across the recipients (LeBlanc et al., 2000). Additionally, services associated with case management were most generally reported as available or not, rather than a report of the quality of the service or the clients' satisfaction. The authors asserted that it is essential that states find a way to meaningfully address implementation quality and client satisfaction.

Lakin and Hewitt (2000) conducted site visits to six states between February and August 2000 to view Medicaid HCBS programs and to discuss the implementation and program outcomes and challenges with key state officials and stakeholders. The selection of the six states was based on a variety of indicators intended to represent HCBS programs on a continuum from relatively "well-developed" programs to those that were still "developing" and the included states were Indiana, Kansas, Louisiana, New Jersey, Wyoming, and Vermont. Extensive case studies were developed for each state. These addressed the state's HCBS programs' purpose, design, assessment, outcomes, and challenges. Three concerns were identified in regard to the current quality assurance systems in the six states and included (a) the limited usefulness of the current system, (b) doubt about the validity of the system, and (c) a feeling that the quality assurance efforts were inefficient and ineffective at producing change. Although many of the participating states conducted consumer satisfaction surveys in one form or another, the authors noted that the information gathered from them was rarely utilized in an effective manner.

Heflinger, Simpkins, Scholle, and Kelleher (2004) conducted a consumer satisfaction study of the Medicaid programs in three states that examined the influence of managed care on the satisfaction ratings of parent/caregiver of children with serious emotional disorders in regard to their children's (a) behavioral health provider, and (b) behavioral health insurance plan. A total of 715 participants were included in the sample: 52% from Pennsylvania, 23% from Tennessee, and 24% from Mississippi. Data were collected in 1997-98 via face-to-face interviews with the parents/caregivers and involved questions that required responses using a 10-point Likert scale. Parents/caregivers were also asked to give grades of A through F to: the number of providers available, the convenience of the provider's location, the range of services covered, and overall quality of behavioral health services under their plan.

Multiple regression modeling techniques were used in the Heflinger et al. (2004) study to analyze the satisfaction ratings and explore the differences between Fee-For-Services and Managed Care plans. The factors of demographic characteristics, clinical measures previously related to satisfaction ratings, and the use of child mental health services in the past six months were controlled for in the study. The results indicated that while the families were generally satisfied with the services from the providers of services, satisfaction ratings for the fee-for-service plan was statistically higher than for managed care service plan. Satisfaction ratings were also influenced by income of the family, with a higher family income having significantly overall lower ratings. Interestingly, African-Americans and older caregivers gave significantly higher satisfaction ratings overall. As part of their conclusions these researchers suggested that addressing the experiences of consumers associated with specific special populations should be a part of the ongoing monitoring and oversight activities of Medicaid programs.

Fralich, Booth, Gray, Bowe, and Bratesman (2005) authored a paper that reviews a

comprehensive collection of data instruments, forms, policies and interviews associated with the discovery methods that are employed within a number of states to enhance their quality management (QM) processes for HCBS programs. The paper synthesizes the ideas and practices that emerged from states that, in 2003, were awarded one of the 19 grants from the Centers for Medicare & Medicaid Services to enhance the quality management for HCBS programs.

A discovery method is a tool for assessing program performance (Fralich et al., 2005). As stated in the HCBS Quality Framework, discovery is the quality management function that involves the process of collecting data, analyzing results, assessing performance and identifying areas of strength and opportunities for improvement. More specifically, discovery methods are tools for assessing the performance of a process, program, policy, provider or contractor and producing data that can be used to guide program management, inform policy development, measure program outcomes, and identify quality improvement areas.

Discovery methods, at a minimum, must address the requirements of the Medicaid waiver and the assurances covered in the Centers for Medicare & Medicaid Services (CMS) Interim Procedural Guidelines (Fralich et al., 2005). One approach that the states have used is mapping the requirements in the Procedural Guidelines against discovery methods and/or data that is available to address that area. Using the CMS Quality Framework (which encompasses the waiver assurance areas) offers a means of expanding beyond minimum requirements. The Framework can serve as a guide for organizing discovery methods and prioritizing potential indicators. Fralich and colleagues (2005) noted that:

The end product of a good discovery method is reliable data that provides ‘evidence’ to support a conclusion or action either at the individual or system level. In order to produce systematic and reliable data, certain core features should be present in a

discovery method (p 7).

These included:

1. Protocols for data collection
2. Qualified reviewers/interviewers
3. Sampling methods that allow conclusions
4. Standard data collection instruments
5. Reliable and accurate data
6. Ability to aggregate, analyze and report data

A report developed by the Kaiser Commission on the Medicaid and the Uninsured (2009) identified the key issues associated with the HCBS waiver programs was based on working group discussion among Medicaid experts. The following issues were among those identified.

1. The need for additional federal financing in order to increase access to Medicaid home and community-based services. At the time of this report a total of 2.8 million individuals currently received Medicaid HCBS, and an additional 300,000 individuals were on a waiting list for services. This represents an 18 percent increase over the previous year.
2. The need to build professional consensus among stakeholders with respect to the measurement of consumer needs.
3. The development of standardized assessment tools to promote equitable access to long-term services and supports.
4. Maintenance of case management services as part of the broader Medicaid benefits package is an essential component to expanding access to HCBS.
5. The growth of attention to workforce development (While more than one million formal caregivers provided paid services in the home in 2007, there are continued shortages of

HCBS workers).

6. The development of systems for sharing information and tracking data between CMS and the states is needed. (The added value of gathering information on best practices and state innovations would help states learn to manage their long-term care programs more effectively.)

Reinke (2009) described Medicaid supports for individuals with autism and while he included useful descriptive information about several of the autism waivers, he did not provide any evaluation data. Shattuck, Grosse, Parish, and Bier (2009) analyzed patterns of utilization and disparity in Wisconsin's Medicaid program for children with autism and found that racial and socioeconomic disparities in Wisconsin autism program utilization have decreased over time.

A study conducted by Eskow, Pineles, and Summers (2011) assessed the impact of the services provided through the Maryland autism waiver on families' perceived quality of life as assessed by comparing responses of families receiving waiver services in Maryland with families in the same state who were on the registry (i.e. waiting list) for waiver services. Specifically, they compared the two groups' responses to questions about their employment situation using the Beach Center Family Quality of Life (FQoL) Scale, developed by Poston and her colleagues (2003) at the University of Kansas. An invitation letter followed by information about how to access an Internet-based survey were sent out to 723 waiver recipients and 2,298 families on the wait-list registry by the state's agency administering the waiver program. Some 861 surveys (229 waiver & 632 registry) were returned, yielding an overall response rate of 28.8% (31.6% waiver & 27.5% registry).

The majority of respondents in both groups reported that having a child with autism

affected their employment (Eskow, Pineles, & Summers, 2011). Interestingly, both groups reported lower satisfaction with their family quality of life than findings from similar studies that included families of young children with less severe disabilities (Summers et al., 2007; Wang et al., 2006). However, the families of children with autism who received waiver services reported higher Family Quality of Life than those not receiving services through the waiver. The authors noted that additional research is needed to more completely understand the waiver's most effective features. They also asserted that more research is needed to determine whether and how waiver programs make a difference in families' quality of life, as well as in health factors, and the children's participation in school, work and leisure activities as well as their effect of on self-determination of outcomes.

A study conducted by Mandell and colleagues (2012) to determine whether the increased provision of community-based services is associated with decreased psychiatric hospitalizations among children with autism spectrum disorders (ASDs). This study employed retrospective cohort of Medicaid-enrolled individuals (N=28 428), aged 5 to 21 years, with an ASD diagnosis. A discrete-time logistic regression was used to examine the association of service use in the preceding 60 days with the risk of hospitalization. It was determined that 2.4% of this group experienced at least 1 psychiatric hospitalization in 2004, and, after adjusting for many patient- and state-level characteristics, the increased use of respite and home/community aide services was associated with an 8% decrease in the risk of psychiatric hospitalizations for the study cohort. However, the use of therapeutic services was not associated with reduced risk of hospitalization. The authors concluded that the availability of respite care should be increased for Medicaid-enrolled children with ASDs. Additionally, based on the lack of association found between therapeutic services and hospitalization, they raised concerns about the effectiveness of

therapeutic services and suggested a need to examine the characteristics and effectiveness of therapeutic services provided to children with autism in the community.

A national review of Home and Community Based Services (HCBS) for individuals with autism spectrum disorders was conducted at the University of Minnesota's Research and Training Center on Community Living (RTC), in collaboration with the Minnesota Leadership Education in Neurodevelopmental Disabilities (MN LEND) program at the University. Data from 2009 to 2010 was gathered from the Centers for Disease Control and Prevention (CDC). A policy research brief, issued by the RTC, summarizes the results of the review and describes how people with ASD are being served across states in Home and Community Based Services, including service eligibility, state trends specific to autism services and lessons learned (Hall-Lande, Hewitt, & Moseley, 2011). At the time the national review data were collected, 11 states offered autism-specific waivers for children (Colorado, Indiana, Kansas, Maryland, Massachusetts, Missouri, Montana, Nebraska, New York [ASD/DD/MR], South Carolina [PDD waiver], and Wisconsin [Children's DD waiver]), and two had autism waivers specific only for adults (Indiana and Pennsylvania).

An analysis of the children's autism waivers revealed variability in the requirements (Hall-Lande, et al., 2011). Some states specifically include children ages eight years and younger (e.g., Colorado, Kansas, Massachusetts, Montana, South Carolina, Wisconsin), while other states extend eligibility from early childhood to young adulthood, such as ages birth-18, 3-18 or ages 1-21 (e.g., Maryland, Missouri, Nebraska, New York). Some states included financial eligibility statements, such as parents' income (e.g., Colorado), whereas other excluded parental income (e.g., Indiana, Maryland, Wisconsin). All children's waivers included eligibility for the diagnosis of autism or ASD, but some states explicitly stated in policy that they extended

services to children with Asperger's syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, and/or developmental disability (e.g. Kansas). Diagnosis by a qualified professional such as a psychologist or pediatrician was required.

The analysis of the children's autism waivers indicated that specific types of services were used to address the specialized needs of children with ASD (Hall-Lande et al., 2011). These services included intensive, in home behavioral therapy (e.g. Applied Behavior Analysis), speech therapy, occupational therapy, social skills training and respite care. Some also included service components such as family therapy.

As authors of the policy research brief of the national review, Hall-Lande et al. (2011) identified the policy needs revealed by the review. They pointed out that the states with autism waivers for children are part of a growing policy trend and that states without these waivers reported a growing need and/or a strong desire to begin creating specialized programs for children with autism. Limitations imposed by current funding were consistently identified as an obstacle to moving forward with these programs.

The two adult autism waivers were viewed as an important policy step towards addressing the needs of adults with ASD by offering specialized services and supports to this population (Hall-Lande et al., 2012). The authors cited the Gerhardt (2009) study that addressed the needs of the children who are part of the first wave of what is often referred to as the "autism epidemic" and currently entering adulthood and his assertion that systems are accessible and designed to meet the needs of adults with ASD are going to be increasingly needed. Finally, the review calls for research that increases our understanding the outcomes of state-specific programs as essential in informing future ASD policy development.

Chapter Three

Methods

This study utilized a mixed methods approach that employed both quantitative and qualitative approaches to research to describe the implementation status of the Kansas Autism Waiver (KAW). This chapter will describe participants, procedures, and data analyses for each of the major methods employed. The quantitative methods are described first and followed by a description of the qualitative methods.

A change to the methodology that should be noted is that a survey was developed and distributed to participants in the waiver as part of the quantitative methodology. However, only 3 parents and 2 service providers responded despite three email requests to the parents and caregivers of the 45 children who were currently served by the waiver and 75 service providers who were associated with the waiver at the time the survey was sent. Therefore, the survey was dropped from the investigation and its procedures are not reported.

Quantitative Methods

This section describes the data sources, the data collection procedures, and the analyses of the demographic variables, service variables and scores on the Vineland Adaptive Behavior Scale scores pertaining to the 57 children who were served by the waiver between January 2008 and November 2010.

Data collection. All measures directed to the quantitative portion of this study were originally collected as part of the ongoing implementation of the Kansas Autism Waiver. Thus, existing data pertaining to the 57 children served by the KAW during the specified time period were obtained from the Kansas Department of Social and Rehabilitation Services (SRS).

Collection of the child demographic and service utilization variables. The child

demographic and service utilization data were obtained from two electronic databases, the Automated Management Information System (AIMS) and the Medicaid Management Information System (MMIS), which are maintained by the Kansas Department of Social and Rehabilitation Services (SRS) Division of Health Care Policy. The AIMS database is the central location for all demographic information regarding individuals served through Medicaid and the MMIS database is the central location of all Medicaid billing and service utilization data.

Because these data are the property of Kansas SRS, prior to providing it to the researcher, all data were de-identified by SRS personnel, this involved removing name and other identifying information and replacing it with the child's birthdate, and then the MMIS and the AIMS data were linked using the micro-identifier of the children's date of birth. In the case of two children having the same date of birth and gender, SRS reported their information separately in order to allow for linkage across the measures.

Collection of the children's Vineland Adaptive Behavior Scale II composite standard scores. The Vineland-II Adaptive Behavior Scale II (VABSII) (Sparrow, Cicchetti, & Balla, 2005, 2006, 2008) is a norm-referenced assessment of self-sufficiency and adaptive skills of individuals from birth through adulthood. According to the Vineland-II Survey Forms Manual the inter-rater and inter-interviewer reliability on the Vineland-II Adaptive Behavior Composite score for ages 0-8, are reported to range from .68 to .80 for the survey interview form. Split-half reliability is reported as ranging from .95 to .98 and test-retest reliabilities ranges from .91 to .96 (Sparrow, Cicchetti, & Balla, 2005).

Each child received an initial Vineland Adaptive Behavior Scales II administration within 10 days of being identified as a KAW recipient. Individuals who serve as the waiver's Functional Eligibility Specialists administer the VABSII as part of each child's initial eligibility

determination and subsequently re-administer it annually for the duration of their participation. The children's VABSII standard scores are compiled by the KAW's Functional Eligibility Specialists and entered into a table that designates each child's name, date of birth, date of administration, their initial scores and, if applicable, each of their annual re-evaluations scores to date. This information is then submitted annually to the KAW program manager.

For the data collection purposes of this study, the KAW program manager removed participating children's names from copies of the tables and provided them to the study's research team. Each child's scores were then linked to their demographic and service utilization data using their date of birth.

Data analyses. The IBM SPSS Version 19 software program was employed to compute both descriptive and inferential statistical analyses. Analyses were conducted relative to the: (a) child demographic variables, (b) child service utilization variables, and (c) the child's standard scores on the Vineland Adaptive Behavior Scale II.

Child demographic data analyses. Percentages, means, ranges and standard deviations were computed for the individual demographic variables of the children's age of KAW entry, gender, ethnicity, and region of residence. Additionally, cross tabulations of the child demographic variables were conducted to identify patterns in these data.

Service utilization data analyses. Percentages, means, ranges and standard deviations were computed for the total number of services used and for the total number of hours provided for each type of service used by the children and families. Additionally, the average hours per week, per month and per year for each type of service were computed. Cross tabulations between the service utilization and demographic variables were also conducted to identify relationships and/or patterns in these data.

Analyses of the changes in the Vineland Adaptive Behavior composite standard scores.

The mean, range, and standard deviation of the children's adaptive behavior composite standard score changes on each of the annual re-administration were calculated. The scores of children with only one administration of the Vineland were not included in the analysis, since change scores could not be tabulated. A Pearson product-moment correlation coefficient with a probability level of .05 was computed to assess the relationship between the change in the standard score and the hours of KAW service received. This analysis is reported for the children at the end of year one due to the number of children with repeated scores.

Qualitative Methods

The qualitative component of this study employed two primary methods: open-ended, semi-structured interviews (Rubin & Rubin, 2005) and focus groups (Cresswell, 1994; Krueger, 1994). The role of the researcher is described initially and followed by a description of the informed consent procedures. Third, the demographics of the participants for each method will be reported. Fourth, the data collection procedures for each of these methods will be described. Finally, the data analyses procedures for the qualitative data overall will be reported.

Role of the researcher. The role of the researcher is critical to the inquiry process in qualitative research that seeks to understand and portray natural settings and events. As such, the researcher is the key instrument of data collection and the characteristics or attributes of the researcher are of relevance to establishing the trustworthiness of the inquiry (Lincoln & Guba, 1985; Patton, 1990).

Although the researcher in this study had completed courses in experimental methodology, she was considered an apprentice in using qualitative methodology. She worked with guidance from an experienced qualitative researcher.

The researcher has held professional roles in the state of Kansas directed to autism intervention and was a member of the committee charged with the development of the KAW. Both her understanding of the KAW and the nature and length of the researcher's participation in the settings of relevance to the waiver positively impacted her ability to collect and interpret data for this inquiry.

Informed consent. Appendices A, B and C contain the informed consent materials. Each informed consent letter delineates the purpose of the study, as well as the procedures, risks, benefits, information to be collected, right of refusal to sign and authorization, and how to cancel consent and authorization developed for this study. This letter and the participation certification were given to each qualitative participant. Appendix A contains the information about the process provided to the parent interview participants, Appendix B contains the information about the process provided to the provider interview participants and Appendix C contains the information about the process provided to the focus group participants. Appendix D contains the questions that were posed to the participants in the interviews and Appendix E contains the questions that were posed to the participants in the focus groups.

Qualitative participants. Participants were recruited from stakeholders in the Kansas Autism Waiver. Participant groups included the parents/primary caregivers of the 45 children who were currently enrolled in the KAW in November 2010 and professionals involved in the Kansas Autism Waiver.

The term "parent/primary caregiver" in this context refers to an adult living with and providing the primary care of the child with autism. Therefore, a parent/caregiver does not necessarily constitute a legal or biological relationship. Parents living apart from the child were not included in the study.

The professionals who participated in the qualitative component of this study were from one of the following groups: Kansas Department of Social and Rehabilitation Services (SRS) administrative staff members, administration staff members of agencies that were contracted by SRS to provide services to the KAW, SRS quality assurance specialists, and enrolled Medicaid providers.

Quality Assurance Specialists (QAS) are individuals who conduct the required Medicaid quality assurance reviews for the children served on the waiver. A total of 23 individuals serve in this role. The specific roles of the KAW Medicaid providers include: autism specialists (AS), intensive individual support providers (IIS), and respite providers (RP). In November 2010, when billing information was downloaded from the MMIS database the number of Medicaid providers by type were as follows: 12 autism specialists, 68 intensive individual support providers and 70 respite providers. Sixty of the 70 respite providers were also enrolled as an autism specialist or an intensive support provider or both.

Table 1 displays the number and roles of the participants for both of the qualitative methods employed in this study.

Table 1

Qualitative Participant Roles

Qualitative Method	Role					Total
	Parent of Child Served on the Waiver	SRS State Level Admin.	Participating Agency Admin.	Quality Assurance Specialist	Medicaid Provider	
Individual Interviews	7				6	13
Focus Group 1		2	3	1	3	9
Focus Group 2				6		6

Note. SRS = Department of Social and Rehabilitation Services

Open-ended, semi-structured interviews participants. All members of the parent/primary caregiver and individual Medicaid provider groups were asked to indicate their willingness to participate in a semi-structured, open-ended interview. Initially two parents and two Medicaid providers indicated their interest in follow up interviews as a result of the failed survey. The investigator then contacted each with more detailed information about the study and the interview process and all four participants returned signed informed consent materials (see Appendix A & B).

Requests for participation in the interviews were then sent out via email to the parents or guardians of the children participating in the KAW and to all Medicaid providers. This strategy did not yield any responses of interest. In recognition of the time involved with interviews, a compensation of \$25 for those who consented to the interview and an additional \$25 upon completion was offered. Four additional parents and 4 additional Medicaid providers were identified using this approach.

Demographic information was collected from the interview participants. Information for the parents included: gender, marital status, number of children in the family, range of family income, and educational level. Demographic information collected for providers included: roles within the waiver, professional designation, educational level, gender, ethnicity, and the number of years working with individuals with disabilities as well as the number of years working in the KAW.

Table 2 sets forth this information for the parents who participated in an open-end semi-structured interview and table 3 displays it for the Medicaid providers.

Table 2

Demographic Profile of Parent Interview Participants

Characteristic	N	%
Gender		
Male	1	14
Female	6	86
Educational Level		
High School Diploma/GED	1	14
Some college but no degree	1	14
Associate degree	3	43
Bachelor's degree	2	29
Race/Ethnicity		
Hispanic (n=0)	0	0
Non-Hispanic (n=7)	7	100
American Indian or Alaska Native (n=0)	0	0
Asian (n=0)	0	0
Black or African American (n=0)	0	0
Caucasian (n=7)	7	100
Unknown (n=0)	0	0
Income Level		
\$16,001-25,000	1	17
\$25,001-35,000	0	0
\$35,001-45,000	1	17
\$45,001-65,000	1	17
\$60,001-85,000	3	50
Marital Status		
Single	1	17
Married	5	83
Number of other Children in home		
0 other children	1	17
1 other child	3	50
2 other children	2	33
Region		
West (Region 1)	1	17
Northeast (Region 2)	4	67
South Central (Region 3)	1	17
Wichita (Region 4)	0	0
Southeast (Region 5)	0	0
KC Metro (Region 6)	0	0
Community		
Urban	1	17
Rural	3	50
Suburban	2	33

Note: Five interviews were conducted with one person & one interview with a couple. All participants are listed in the gender, ethnicity, and ed. level categories; the couple is counted singularly in all others.

As can be noted from Table 2, the problems with obtaining interested interview participants limited the diversity of the parents interviewed. Six of the seven parents were female, and the only male that participated did so with his wife. All 7 (100%) of the parents were Caucasian, whereas 44 (77%) of the 57 children served by the waiver during the period pertaining to this study were Caucasian. One parent noted that although they were Caucasian, their child was African-American. Only one parent reported their status as single, never married.

Some differentiation occurred within the educational attainment of the interviewed parents. Five (71%) of the parents had from some college to a bachelor's degree. The parents also represent a wide economic range, however 4 (67%) of the 6 families represent the top two income groups of \$45,001-\$65,000, and \$60,001-\$85,000.

Three of the six Kansas geographical service regions identified by SRS at the time this study was conducted are represented. These include the Northeast, Region 2, the South Central Region 3 and the West Region 1. One parent (17%) was from the West, Region 1, an area that served four (7%) of the children in the waiver. Four (67%) of the parents (the husband and wife are counted singly for this variable) were from the Northeast region of the state, an area that served 23% of the children in the waiver and one parent (17%) was from the South Central Region 3, an area which served, 6 (10.5%) of the children in the waiver. Regions that were not represented included the KC Metro, Wichita, and Southeast region of the state that respectively represent 29.8%, 28.1% and 1.8% of the total children served by the waiver. All three types of the communities; urban, suburban and rural were represented by the parents.

Interviews of six Medicaid providers who provided services to children served by the waiver were conducted. These providers included two autism specialists, one provider who was

dually enrolled as an autism specialist and an intensive individual support provider, two providers who were dually enrolled as intensive individual support providers and respite providers and one provider who was singly enrolled as an intensive individual support. Table 3 displays the demographic profile of these professionals.

Table 3

Demographic Profile of Medicaid Provider Interview Participants

Characteristic	N	%
Gender		
Male	1	17
Female	5	83
Ethnicity		
Hispanic	1	17 ^a
Non-Hispanic	5	83
American Indian or Alaska Native	0	0
Asian (n=0)	0	0
Black or African American	0	0
Caucasian	6	100
Unknown	0	0
Educational Level		
High School Diploma/GED	0	0
Some college but no degree	1	17
Bachelor's degree	2	33
Master's degree	3	50
Doctorate	0	0
Region		
West (Region 1)	1	17
Northeast (Region 2)	4	67
South Central (Region 3)	2	33
Wichita (Region 4)	2	33
Southeast (Region 5)	0	0
KC Metro (Region 6)	1	0

Note: The number of Medicaid Providers listed under Region exceeds the number of providers interviewed (6) because a number of these providers serve in multiple regions and identified each region in which he or she served.

^a This participant identified themselves as a Caucasian Hispanic.

As can be noted from Table 3, all of the providers who participated in the open-ended interview are Caucasian with one individual (17%) reporting Hispanic Caucasian ethnicity. No

other racial/ethnic groups are represented. These participants represented varying educational levels from some college to master's degrees. While the providers of respite care are not required to have any college, the two respite providers who participated in this interview had dual KAW roles. Additionally, to serve as an autism specialist an individual must have no less than a Master's degree.

Tables 4 and 5 provide information about the Medicaid providers work experience with individual with disabilities, and within the KAW respectively. As depicted in Tables 4 and 5 the Medicaid providers have a greater range in their years of experience working with individuals with disabilities than working within the Kansas Autism Waiver because their waiver experience was limited by the fact that this study addressed the first 35 months of the KAW. The providers' experience working with individuals with disabilities ranged from 2-3 years to 23-40 years, whereas their experience working within the KAW ranged from 2 through 4 years.

Table 4

Medicaid Provider Interview Participants' Experience Working with Individuals with Disabilities

Years	N	%
23 - 40	1	17
19 - 22	0	0
14 - 18	0	0
6 - 13	2	33
4 - 5	1	17
3 - 4	0	0
2 - 3	2	33
1 - 2	0	0
Under a year	0	0

Table 5

Medicaid Provider Interview Participants' Experience Working in the KAW

Years	N	%
3 – 4	2	33
2 – 3	4	67
1 – 2	0	0
Under a year	0	0

Note. KAW = Kansas Autism Waiver

Focus group participants. Two focus groups were held for the purpose gaining insight into the perceptions of additional key members the KAW. One focus group was comprised of the members of KS Autism Steering Committee and the other focus group was conducted with Quality Management Specialists.

The Autism Steering Committee is made up of three state level support staff and ten members who are invited by Social and Rehabilitation Services (SRS), Department of Behavioral Health Services (DBHS) to be a part of the committee. The invited members included parents of children with autism, professionals working in the field of Autism and/or Education and providers (from independent service agencies that are eligible for Medicaid reimbursement). The Committee meets on a quarterly basis to discuss current policies and /or the development of policies, legislative issues, evidence-based practices, and to make recommendations concerning the Autism Waiver to Social Rehabilitation Services Disability and Behavioral Health Services, Community Supports and Services.

Quality Management Specialists (QMS) are employees of Kansas Social and Rehabilitation Services who are tasked with annually reviewing the implementation of the seven waivers administered by Community Supports and Services. These waivers have varying expectations for the percent of participants that must be included in a review. Due to the small

size of the Kansas Autism Waiver, the percent of participants that must be included in the yearly review for the KAW is 100%. Reviews include an inspection of individual files and interviews of families and KAW providers about the implementation of services.

Table 6 displays the demographic profile of the participants in the Autism Steering Committee (ASC) focus group and the Quality Management Specialists (QMS) focus group.

Table 6

Demographic Profile of the Focus Group Participants

Characteristic	ASC Group (n = 9)		QMS Group (n = 6)	
	N	%	N	%
Gender				
Male	0	0	0	0
Female	9	100	6	100
Role within the Waiver				
Administrators	4	44	0	0
Program Supervisor	3	33	0	0
Autism Specialist	1	11	0	0
Direct Service Provider	3	33	0	0
State Level Administrator	2	22	0	0
Quality Management Specialist	1	11	6	100
Educational Level				
High School/GED	0	0	0	0
Some college but no degree	0	0	1	17
Bachelor's degree	0	0	3	50
Master's degree	6	67	2	33
Doctorate	3	33	0	0

Note. ASC = Autism Steering Committee; QMS = Quality Management Specialist
The participant numbers within the Roles within the Waiver exceed total because many participants self-identified with multiple roles

As can be noted from Table 6, the Autism Steering Committee focus group participants represent a diverse group of roles, whereas the Quality Management Specialist focus group is only comprised of Quality Management Specialists. All of the participants in both groups were women. The Autism Steering Committee group's nine participants held either master's degrees (6) or doctoral degrees (3), whereas the Quality Management Specialist group ranged in

educational level from some college through a master's degree, with three of the six holding bachelors' degrees and two of the six holding master's degrees.

Tables 7 and 8 provide information about the focus group participants work experience with individual with disabilities and within the KAW respectively.

Table 7

Focus Group Participants Experience with Individuals with Disabilities

Years	ASC Group (n = 9)		QMS Group (n = 6)	
	N	%	N	%
23-40	2	22	0	0
19-22	3	33	0	0
14-18	2	22	0	0
6-13	2	22	5	83
4-5	0	0	0	0
3-4	0	0	0	0
2-3	0	0	1	17
1-2	0	0	0	0
Under a year	0	0	0	0

Note. ASC = Autism Steering Committee; QMS = Quality Management Specialist

Table 8

Focus Group Participants Experience within the Kansas Autism Waiver

Years	ASC (n = 9)		QMS (n = 6)	
	N	%	N	%
3-4	5	56	2	33
2-3	3	33	4	67
1-2	0	0	0	0
Under a year	1	11	0	0

Note. ASC = Autism Steering Committee; QMS = Quality Management Specialist

As can be noted in Table 7, the participant's number of years of working within the disability field ranged from 6-13 years from 2-3 years to 3-4 years. And, as depicted in tables 7 and 8, the participants have a greater range in their years of experience working with individuals

with disabilities than working within the Kansas Autism Waiver because the waiver experience was limited by the fact that this study addressed the first four years of the KAW.

Qualitative data collection. The following section describes the qualitative data collection procedures. First the equipment and materials will be described and includes the equipment utilized for documenting the interviews and the materials developed to guide the questioning in the interviews and focus group. A description of the semi-structured interview and focus group procedures follows.

Equipment and materials. The interviews and focus group were all audio-recorded. Additionally, the researcher prepared written questions that served as guides for the interviews and for the focus groups to ensure that topics across the participants were consistently addressed. The equipment is briefly described first, followed by description of the preparation and content of the guides

Audio recording equipment. The interviews and the focus group that were conducted by telephone used the Leader Phone® Teleconference system. This system includes an internal recording option and each of these interviews and the focus group were recorded using this option. Each recording was emailed to the researcher as a password protected .wav file with the date and time of the recording. Once an interview file was received, the researcher added the identification code for each interview participant and for the focus group conducted by telephone.

A SONY PCM-M10 Digital Audio Recorder was used to audio-record the in-person interview and the in-person focus group. This audio recording device is battery powered and can record MP3 or WAV files at rates up to 24-bit/96kHz. The audio recording was transferred

to the researcher's computer, labeled with the code and date for this focus group and password protected.

Question guides. Appendix D and E include the interview guides that was developed to facilitate the content focus of the parent and provider interviews and Appendix F contains the guide developed for the telephone focus groups. All of the guides ensured that each interviewee and both focus groups had an opportunity to respond to the same questions of relevance to the implementation of the waiver.

Questions for the guides were developed from reviews of the published literature addressing quality assurance of services provided within program for individuals with disabilities (CMS, 2004; Lakin & Prouty, 2003; National Committee for Quality Assurance, n.d.; Ronder, Kastner, Parker, & Walsh, 1999; Schalock, 1995; Siegel, 2002) and (b) implementation and evaluation research in the social sciences (Fixsen, Naoom, Blasé, Friedman, & Wallace, 2005; Patton, 2008). Additionally, the primary researcher's experience in the current waiver system was useful in developing the guides.

All of the guides contained questions related to the functions of the waiver, including the assessment process to determine eligibility, assessment for program planning, services and interventions. The results of the child demographic profiles, use of the KAW services and the Vineland II score changes were considered in the development of the questions. Additionally, the implementation of recommended practices and needs for changes to the system were addressed.

Open-ended, semi-structured interviews. A semi-structured, in-depth interview procedure using open-ended guiding questions was employed to interview the participants who served as key informants on experiences with the waiver's implementation. The value inherent

in the open-ended question is the individuality of the obtained responses (Fraenkel & Wallen, 2000).

Every effort was made to conduct the interviews in a manner, time and place of convenience to the interviewee. The interviews of the parent/caregivers and providers occurred primarily by phone. Six of the seven parents and five of the six providers participated in phone interviews. One provider requested and participated in a face-to-face interview and one parent participated in a face-to-face interview with a follow up phone call.

Once the parents and Medicaid providers agreed to participate in the study, a convenient time for both the interviewee and the interviewer was determined. Two researchers were present for each phone and face-to-face interviews, although the lead researcher took primary responsibility for guiding the interview. Interviews typically lasted between 30 minutes and an hour. While the interviews were taped, both researchers also took detailed notes and, following each interview, discussed and compiled the notes to be used as a resource when analyzing data. Each interview began with some general guidelines including a request to audiotape the interview and a reminder that if they did not want to answer any questions the interviewee could feel free to let us know. When consent was given, the recording and interview began simultaneously.

Although the guiding questions were available to the participants and used by the researcher as means of ensuring key topics were addressed (See Appendices D-F), participants often added additional content of relevance to them during the interview process. As appropriate to the semi-structured and open-ended interview process, the interviewees as well as the researcher were allowed opportunities for expansion, clarification, or additional questions during the interview session. Issues that emerged during interview sessions were used to formulate

questions for follow up interviews with some participants. After each interview was completed, the research team transcribed the recording.

Focus groups. A focus group is a group of people, usually between 6 and 12, who are brought together for a somewhat opened-ended discussion in response to questions about their perceptions, experiences and or opinions about a program, a service, or a product. A moderator guides the discussion and encourages participants to freely discuss their feelings, concerns, and recommendations about the topic of focus (Krueger & Casey, 2000).

As indicated, two focus groups were held for the purpose of gaining insight into the perceptions of members of KS Autism Steering Committee and individuals who served as Quality Management Specialists for the KAW. The Autism Steering Committee has quarterly meetings at offices in Topeka, Kansas, therefore their focus group occurred at the scheduled time and place of one of the quarterly meetings, just prior to commencement of the formal meeting. Due to inclement weather the Quality Management Specialist focus group was conducted via a telephone conference call.

The individual who assisted the lead researcher with the interviews moderated both focus groups. The assistant in the interview sessions had experience moderating conference-based meetings, including extensive experience coordinating telephone focus groups. Focus group session guides were developed for the questioning and discussion. Appendix F contains a copy of the telephone focus group guide.

Each focus group began with some general guidelines including a request to audio record the interview and a reminder that if they did not want to answer any questions they could feel free to let the researcher know. Additionally, the general guidelines included a request that each speaker in the focus group begin their statements with their name to facilitate pairing the

statements with the speaker. When consent was given, the interviews recording device was turned on and the focus group began.

The Autism Steering Committee focus group was conducted in person. The participants were seated at a circular table. The participants chose their seats when they entered and were given name cards.

The Autism Steering Committee focus group was audio recorded, an assistant took notes during the focus group session and these notes included the location of the different responders and noted dynamics of the group. These notes were not utilized during the coding of the group, but if there had been confusion regarding participant responses then were used to confirm speakers during the session.

Immediately following the Autism Steering Committee focus group session, the moderator and assistant moderator debriefed and documented impressions, themes, important points and quotes, surprising results and any lessons learned to apply to the next focus group. The digital audio recording was transcribed by an individual with experience recording focus group transcripts.

The Quality Management Specialists focus group, as previously noted, was a telephone focus group that was conducted utilizing the Leader Phone® Teleconference system. Quality Management Specialists already participate in regularly scheduled meetings via this system so these focus group participants were comfortable with the process.

This focus group session was also digitally audio recorded with the audio taping option provided by the Leader Phone® Teleconference system. Due to the lack of face-to-face interactions, more opportunities were provided to ask each member if they had a comment in regard to a specific question. Immediately following the Quality Management Specialists focus

group session, the moderator and assistant moderator debriefed and documented impressions, themes, important points and quotes, surprising results. The research team then transcribed the audio recording of the quality management specialist focus group.

Qualitative data analysis. The constant comparative method of data analysis (Bogdan & Biklen, 1998; Denzin & Lincoln, 2007; Glaser & Strauss, 1967; Merriam, 1998; Miles & Huberman, 1994; Patton, 2002) was used to analyze the data from focus group and interview transcripts. The same two researchers who conducted the interviews and focus groups conducted this process. In a constant comparative method, successively abstract concepts are generated through a series of inductive processes of comparing data with data. Essentially informational units from the interview and focus group transcripts (i.e. data sources) that represented individual “chunks” of information capturing single ideas or thoughts were identified and then sorted into categories and concepts (Charmaz, 2006). Categories were assigned yet considered emergent in that they developed as the research team studied and discussed the data. Data were continually compared to all other data to identify similarities, differences, and emergent patterns. Through a process of organizing and re-organizing the chunks of data and categories, a final category scheme was generated that contains all relevant data collected.

Each interview participant was assigned a pseudonym and his or her transcript was coded. The interview transcript content was then unitized into individual chunks or units of data and separated from the transcripts. The units carried the identifying codes so that each could be traced to its source transcript.

Each focus group participant was also assigned a pseudonym and each incidence of the individual participant’s comments was coded within the focus group transcript. Individual data units were then determined and separated from the transcripts. The units carried the identifying

codes so that each could be traced directly to its place in the source transcript and to the speaker's pseudonym and role.

Analysis of the data began with the completion of the first interview. During the process of the unitization and categorization of data analyses, the research team developed a codebook that identified the emergent categories and their corresponding data units. Throughout this constant comparison of data, the research team discussed areas of agreement and confusion, cross continually revising and refining the categories and cross checking each other's coding until the final categories emerged. A total of 13 codebooks were developed during this process.

Trustworthiness of the Data Analyses

Triangulation is a process central to ensuring that the findings of a mixed method study can be viewed as credible (Cresswell & Plano Clark, 2011; Denzin & Lincoln, 2007).

Triangulation involves crosschecking information and conclusions from multiple procedures or sources to establish incidences of agreement or corroboration.

Investigations that employ multiple methodologies ensure that different data forms (i.e. types of data) are available as a means of corroboration that give rise to emergent constructs and themes. This is generally referred to as methods triangulation. For example, in the present study, the multiple methodologies involved quantitative descriptive statistical analyses, correlational analyses as well as qualitative analyses of interview and focus group narratives. When multiple sources are used as a means of corroboration, it is referred to as data triangulation. In this study data sources included child demographics, service use, test scores, individual interviews and focus group interviews, as well as participant observation notes. Through this process of triangulation overarching constructs and themes emerged which are grounded in the data.

Chapter 4

Quantitative Results

The results the research questions for which quantitative methodology was employed are reported in this chapter. These four questions address the implementation context and outcomes of the KAW based on analyses of child demographic variables, service utilization variables and the Adaptive Behavior Composite score changes on the Vineland Adaptive Behavior Scale II. Each question is presented with corresponding results following in order. The first question is presented next.

Research Question 1

What do the child demographic variables indicate about the characteristics of the children selected for participation in the KAW? Table 9 displays demographic information that was obtained from the KS Social Rehabilitation System's Automated Management Information System (AIMS) and subsequently analyzed for the 57 children participating in the KAW between January 2008 and November 2010. All 57 children qualified for the waiver by having an autism spectrum disorder diagnosis and meeting the functional eligibility criteria for the waiver.

Table 9

Demographic Profile of Children Served in KAW: 1/1/08 – 11/30/10

Characteristic	N	%
Gender		
Male	49	86.0
Female	8	14.0
Race/Ethnicity		
Hispanic	5	8.8
Non-Hispanic	52	91.2
American Indian or Alaska Native	4	7.0
Asian	3	5.3
Black or African American	6	10.5
White	40	70.2
Unknown	4	7.0
Entry Age ^a		
2 years to 2 years 182 days	1	1.8
2 years 183 days to 2 years 364 days	0	0.0
3 years to 3 years 182 days	9	15.8
3 years 183 days to 3 years 364 days	7	12.3
4 years to 4 years 182 days	6	10.5
4 years 183 days to 4 years 364 days	19	33.3
5 years to 5 years 182 days	8	14.0
5 years 182 days to 5 years 364 days	7	12.3
SRS Region		
West (Region 1)	4	7.0
Northeast (Region 2)	13	22.8
South Central (Region 3)	6	10.5
Wichita (Region 4)	19	28.1
Southeast (Region 5)	1	1.8
KC Metro (Region 6)	16	29.8

Note. KAW = Kansas Autism Waiver, SRS = Department of Social and Rehabilitation Services

^a Entry Age: M = 4.49, Range = 2.14-5.96, SD= .85

Table 9 reveals that 49 or 85% of the children served by the waiver were boys. This predominance of boys reflects national prevalence data reported by the Center for Disease Control and Prevention, which is based on a 2006 study that reports that autism is on the average four to five times more likely to occur in boys than in girls in the U.S. (CDC, 2009).

The percentages of the ethnic/racial groups reported in Table 9 are consistent with the U.S. Census Bureau's 2010 census report of ethnic/racial percentages in Kansas. Specifically,

the 2010 Kansas racial/ethnicity data are as follows: White, 78.2%, Black, 5.9%, Hispanic, 10.5%, American Indian or Alaska Native, 1%, Asian 2.4%, and persons reporting two or more racial groups, 3% (2010). These data indicate that the KAW seems to be providing services to the various ethnic/racial groups in Kansas on an equitable basis.

Although services were provided across the state, the number of children served by the waiver in each region varies significantly. Eighty five percent or 49 of the 57 of the children served were from three Kansas SRS regions, KC Metro, Wichita and the Northeast, which includes, Topeka and Manhattan. These three regions have the largest combined population base of Kansas. KAW services were only provided to 1 child or 1.8% of the children served in the Southeast region, which is only comprised of rural communities. Thus, the West region, which is also very rural but represents the largest number of square miles, in combination with the South Central region, served 10 children, which was 17.5% of the children served by the waiver.

Finally, is also interesting to note that despite the intent of the waiver to identify children as young as possible, Table 9 reveals that only 17 or 30 % began services within their second and third years of age, whereas 40 of the 57 or 70% of the children began services within their third and fourth years of age. Based on these data, the children's mean age at entry to the program was 4.49 years ($SD = .85$) and ranged from 2.14 years to 5.96 years.

Table 10 displays the number of children by ethnicity/racial group for each of the SRS regions during the first 35 months of the waiver. Table 10 displays the number of children by ethnicity/racial group for each of the SRS regions during the first 35 months of the waiver.

Table 10

KAW Participants' Ethnicity/Race Within the SRS Regions of Residence: 1/1/08 – 11/30/10

Ethnicity/Race	Region					
	West (n=4)	Northeast (n=13)	South Central (n=6)	Wichita (n=16)	Southeast (n=1)	KC Metro (n=17)
Hispanic (n=5)	0	0	1	1	0	3
Non-Hispanic (n=52)	4	13	5	15	1	14
American Indian or Alaska Native (n=4)	0	1	0	1	0	2
Asian (n=3)	1	0	0	1	0	1
African American (n=6)	1	3	0	2	0	0
White (n=40)	2	8	6	12	1	11
Unknown (n=4)	0	1	0	0	0	3

Note. KAW = Kansas Autism Waiver, SRS = Department of Social and Rehabilitation Services

Table 10 reveals that the most populated districts, KC Metro, Wichita and the Northeast, account for majority of the children from ethnic/racial categories other than White-Non Hispanic. The combined regions KAW participants during the first 35 months of implementation included 3 of the 4 children of Hispanic ethnicity, 5 of the 6 African American children, and 4 of the 4 children of American Indian or Alaska Natives ethnicity. Additionally, 2 of the 3 children who participated in the waiver from these three regions were Asian. Finally, the Wichita region had the most children from ethnic/racial categories other than White-Non Hispanic within a single SRS region.

Research Question 2

What do the data pertaining to KAW services used by the children and families indicate about its implementation? Fifty seven children participated in the KAW during the initial 35 months from January 1, 2008 to November 30, 2010, with only 45 total participants during a given time period. Children were considered a participant at the point they were

determined to be eligible, and therefore the length of participation for each child was based on the date of each child's eligibility determination to their date of exit from the waiver. Many children waited several months between their eligibility determination and the onset of service. Therefore, the months in which services were received ranged from 0 months (i.e. children near the end of the initial 35 months who had not yet received a bill for services) to the full 35 months. The mean number of months that these 57 children received services in the KAW was 20.42 months with a standard deviation 9.87 months.

The number of monthly service hours provided per child over the course of their participation ranged from 0 to 104.02 hours with a mean of 38.20 and standard deviation of 27.63 monthly service hours. The potential for accounting for a one-time extension of service from 36 to 48 months was not possible given that this study targeted the initial 35 months.

Table 11 reports the hours of monthly and weekly usage of each type of service provided in the KAW across the 57 children served during the initial 35 months. An inspection of Table 11

KAW Participant Service Hours by Service Type: 1/1/2008 – 11/30/2010.

Service	Hours Per Month			Hours Per Week		
	Range	<i>M</i>	SD	Range	<i>M</i>	SD
AS	0 - 12.2	4.38	2.6	0 - 2.84	1.02	.61
IIS	0 - 92.0	31.05	24.99	0 - 21.44	7.22	5.81
FAC	0 - .4	.2	.06	0 - .09	.003	.02
RC	0 - 15.81	2.62	4.10	0 - 3.68	.61	.95
PST	0 - 1.38	.14	.34	0 - .32	.03	.07

Note. KAW = Kansas Autism Waiver; AS = Autism Specialist; IIS = Intensive Individual Support; FAC = Family Adjustment Counseling; RC = Respite Care; PST = Parent Support and Training

11 reveals both substantial ranges of service hours as well as standard deviations that are often similar to the means, indicating the considerable variability in the hours of service being received

by the KAW participants. The service with the highest frequency of use was the Intensive Individual Support Service (IIS), which had a weekly range of 0 to 21.44 hours per week with a mean of 7.22 hours per week with a standard deviation of 5.81 hours per week.

The Autism Specialist Service (AS) was next in frequency of use. The services of an Autism Specialist include oversight of program services and interventions as well as consultation with the family and the direct service providers. This service had a weekly range of 0 to 2.84 hours of use per week with a mean of 1.02 hours per week.

The Respite Care (RC) service was third in frequency of use, with a range of 0 to 3.68 hours per week and mean of .61 or about 37 minutes per week.

The Parent Support and Training (PST) and Family Adjustment Counseling (FAC) services are both provided directly to the parents or caregivers. These two services represent the lowest frequency of use. The range of monthly use of the PST services was from 0 to 1.38 hours per month with an average monthly use of .34 or about 30 minutes per month. The FAC was even lower with a range of .4 or 24 minutes per month with a mean of .2 or 12 minutes per month.

Table 12 compares the allotted (i.e. maximum number of allowed service hours) average monthly and weekly hours of each of the service types with the mean of KAW monthly and weekly service hours that were actually provided during the first 35 months of the implementation.

Table 12

Allotted and Used KAW Service Hours: 1/1/08 – 11/30/10

Service Type	Allotted ^a Monthly Hrs.	Mean of Hrs. Used	Allotted ^a Weekly Hrs	Mean of Hrs. Used
AS	4.16 ^{bd}	4.38	.96	1.02
IIS	104.00 ^b	31.05	25.00	7.22
FAC	1.00	.20	.23 ^c	.003
RC	14.00	2.62	3.23 ^c	.61
PST	2.50	.14	.58 ^c	.03

Note. KAW = Kansas Autism Waiver; Hrs. = Hours; AS = Autism Specialist; IIS = Intensive Individual Support; FAC = Family Adjustment Counseling; RC = Respite Care; PST = Parent Support and Training.

^a Allotted is the maximum number allowed KAW service hours.

^b Hours are computed on the basis of 4.1 weeks per month.

^d AS is the only service the waiver allows additional hours upon request

As indicated in table 12, the Autism Specialist service is the only service type for which the waiver allows additional hours to exceed the allotted hours that can be granted upon request. And, interestingly, as indicated in Table 12, the mean monthly hours used for the Autism Specialist (AS) services (4.38 or 4 hours and 23 minutes) slightly exceeds the maximum of 50 hours per year or 4.16 hour per month (i.e. 4 hours and 8 minutes) that the waiver allows for these services.

The comparisons of the remaining four service types all reveal substantially lower mean hours of monthly use in comparison to the maximum monthly hours allotted within the waiver. As can be noted in the previous table, Table 11, the Intensive Individual Supports service upper end of the range of used monthly hours (92) is close to the 104 hours per month allotted for the Intensive Individual Supports service displayed in Table 12. However, as revealed in Table 12, the mean monthly hours actually used for these services (31.05 hours or 31 hours and 3 minutes) are markedly lower than the 104 hours per month allowed by the waiver. The mean number of

hours used for Respite Care (RC) services per month, 2.62 hours (i.e. 2 hours and 37 minutes) is also substantially lower than the maximum of 168 hours per year or 14 hours per month that are provided for in the waiver. Table 12 also shows that the mean number of hours used for Parent Support and Training (PST) was .03 hours (i.e. 2 minutes per month) is much lower than the average of 2.5 hours per month that are provided for in the waiver (which is computed on the basis of a maximum of 30 allotted yearly hours). Finally, Table 12 shows that the mean monthly hours provided for Family Adjustment Counseling (FAC) is one hour per month, but that it is used on the average of just .2 of an hour or 12 minutes per month.

Table 13 lists the average hours of monthly usage of each type of KAW service as well as the total number of monthly service hours across service types by region during the first 35 months of the KAW. The differences among the total or overall services hours provided within the six regions are large. For example, the mean of the total monthly service hours in the Southeast region is 21.29, which is less than half of the 50.18 of the monthly service hours provided in the South Central region. Interestingly, both of these regions are primarily rural.

Table 13

Average Monthly Hours of Service Use Within SRS Regions: 1/1/08 – 11/30/10

Region	Mean of Monthly Service Hours					Total
	AS	IIS	FAC	RC	PST	
West (n=4)	5.31	25.19	.0	1.17	.01	31.67
Northeast (n= 13)	4.79	34.84	.0	2.44	.14	42.22
South Central (n=6)	1.19	41.06	.003	3.91	.10	50.18
Wichita (n=16)	4.09	23.59	.0	1.33	.16	29.17
Southeast (n=1)	4.13	17.15	0	0	0	21.29
KC Metro (n=17)	3.88	33.82	.05	4.02	.17	41.94

Note. KAW = Kansas Autism Waiver; SRS = Department of Social and Rehabilitation Services; AS = Autism Specialist; IIS = Intensive Individual Support; FAC = Family Adjustment Counseling; RC = Respite Care; PST = Parent Support and Training.

An inspection of the differences in the specific types of service monthly hour means reported in Table 13 is also interesting. The Autism Specialist ranged from 1.19 hours per month in the South Central region to 5.31 hours in the West region. Intensive Individual Supports ranged from 17.15 hours per month in the Southeast region to 41.06 hours per month in the South Central region. Family Adjustment Counseling ranged from no usage in four regions to just .05 or 3 minutes of monthly use in the KC Metro region. Respite Care ranged from no usage in the Southeast region to 4.02 hours per month in the KC Metro region. Parent Support and Training ranged from no usage in the Southeast region to .17 of hour or 10.2 minutes in the KC Metro region.

Finally, as reported in Table 13, Family Adjustment Counseling was only provided in two of the six regions of the state: the KC Metro, an urban region, and the South Central region, a rural region. Usage in both of these regions was very low, and therefore, these data could be related to the small number of providers enrolled for that Family Adjustment Counseling as well a limited demand for this service. While all but one region, the Southeast region used Parent Support and Training, this service has the lowest usage across the regions. Interestingly, the Southeast region was the region with the highest overall mean of monthly service hours

Table 14 provides more specific information on the use of services within each region and reports the number of children within that region who used each service across the initial 35 months of implementation.

Table 14

KAW Service Use by Children and Type Within SRS Regions: 1/1/08 – 11/30/10

Region	N of Children Using Service ^a	Service Type	Monthly Hours		Weekly Hours	
			M	SD	M	SD
West (n=5)						
	4	AS	5.31	3.88	1.24	.90
	4	IIS	25.19	22.87	5.86	5.32
	0	FAC	.0	.0	.0	.0
	2	RC	1.17	1.57	.28	.36
	1	PST	.01	.02	.002	.005
	4	Total	31.67	27.21		
Northeast (n=13)						
	12	AS	4.79	3.12	1.12	.73
	12	IIS	34.84	25.55	8.10	5.94
	0	FAC	0	0	0	0
	8	RC	2.44	2.90	.57	.67
	5	PST	.14	.36	.03	.08
	12	Total	42.22	28.45		
South Central (n=6)						
	5	AS	1.19	4.00	1.19	.93
	5	IIS	41.06	38.13	9.55	8.87
	1	FAC	.003	.008	.002	.004
	3	RC	3.91	6.00	.91	1.40
	3	PST	.10	.19	.02	.04
	5	Total	50.18	44.21		
Wichita (n=16)						
	15	AS	4.09	2.28	.95	.53
	15	IIS	23.59	19.87	5.49	4.62
	0	FAC	.0	.0	.0	.00
	4	RC	1.33	3.53	.31	.82
	5	PST	.16	.36	.038	.08
	15	Total	29.17	21.30		
Southeast (n=1)						
	1	AS	4.13	0	.96	0
	1	IIS	17.15	0	3.99	0
	0	FAC	0	0	0	0
	0	RC	0	0	0	0
	0	PST	0	0	0	0
	1	Total	21.29	0		
KC Metro (n=17)						
	16	AS	3.88	1.74	.90	.61
	16	IIS	33.82	25.30	7.87	5.88
	3	FAC	.05	.12	.01	.03
	11	RC	4.02	4.90	0.93	1.14
	4	PST	.17	.12	0.04	.03
	16	Total	41.94	27.64		

Note. KAW = Kaw Autism Waiver; SRS = Department of Social and Rehabilitation Services; AS = Autism Specialist; IIS = Intensive Individual Support; FAC = Family Adjustment Counseling; RC = Respite Care; PST = Parent Support and Training.

^aNumber of children who were billed for a service during the initial 35 months of the KAW.

Table 14 indicates that in all regions except the Southeast region, not all of the children identified as eligible in the region received services during the first 35 months of implementation. Specifically, five children (one child per region across the five regions) received no services.

Table 14 also shows that the Autism Specialist (AS) and Intensive Individual Supports (IIS) were the two services used by all of the children who received services across the six SRS regions. Family Adjustment Counseling (FAC) was the least used service across the waiver with only four children's parents (i.e. three in the Kansas City Metro region and one child's parents in the South Central region) using that service. Both child and family needs and the availability of providers could have impacted the usage of that service. The Parent Support and Training service also had very low usage across the five regions that used the service, with no use of this service in the Southeast region

The use of the respite care services varied across the regions. Of note is the difference in the use of respite care services in the two urban regions with highest numbers of children served by the KAW: the Wichita region and the Kansas City Metro region. Only four of the 15 families received respite care in the Wichita region, whereas 11 of the 16 families in the Kansas City Metro region received respite care. This service was also used in the Northeast by eight of 12 families, in the South Central region by three of five families, and in the West region by two of four families. The Southeast region's single family did not use respite care.

Research Question 3

Do the children's Adaptive Behavior Composite standard scores change from the initial to the repeated administration of the Vineland Adaptive Behavior Scale II and if so what is the direction and degree of change? All children are assessed with the survey form of

the Vineland Adaptive Behavior Scales II (VABSII) (Sparrow, Cicchetti, & Balla, 2005, 2006, 2008) as part of the eligibility determination. If determined to be eligible, this assessment is administered annually thereafter. During the first 35 months of the waiver a total of 57 children received services and all 57 children received an initial evaluation. Subsequently, 50 children received a first annual re-evaluation, 38 received a second annual re-evaluation, and 11 received a third annual re-evaluation.

Table 15 displays the children's Vineland's adaptive behavior composite standard score means as well as the score ranges and standard deviations for their initial evaluations through their third annual re-evaluations. As indicated in the table notes, in each of case of the yearly reevaluations, some of the children's scores were removed due to a determination of scoring errors.

The Behavior Composite mean standard scores for the initial, first and second year administrations of the Vineland reported in Table 15 for the children participating in the KAW fall between the mean scores obtained by the subset of children with autism in the clinical reference group reported in the Vineland II Survey Forms Manual. According to the Vineland II Survey Forms Manual, children with nonverbal autism ages 3-15, obtained a mean score of 50.7 on the Adaptive Behavior Composite, and children with autism who were verbal obtained a mean score of 65.7.

Table 15

*Adaptive Behavior Composite Standard Scores Obtained by Children Participating in the KAW**Across Four Administrations: 1/1/08 – 11/30/10*

Administration	Child <i>n</i>	Standard Scores		
		Range	<i>M</i>	<i>SD</i>
Initial evaluation	57	40 – 79	60.11	9.60
First annual reevaluation	46 ^a	46 – 82	60.39	8.39
Second annual reevaluation	33 ^b	47 – 94	62.94	11.24
Third annual reevaluation	5 ^c	50 – 89	71.80	14.06

Note: KAW = Kansas Autism Waiver

^a=adjusted from 50 to 46 due to removal of 4 scores outside range of expected scores; ^b= adjusted from 38 to 33 due to 5 scores outside range of expected scores; ^c=adjusted from 11 to 5 due to 6 scores outside of the range of expected scores.

As can be noted from Table 15, the means of the Adaptive Behavior Standard Scores were fairly consistent among the initial, the first, and second annual re-evaluations (60.11, 60.39, 62.94 respectively) as were their standard deviations (9.60, 8.394 and 11.239 respectively). The mean standard scores of these remaining five children represents the largest overall positive increase in the yearly mean of the standard scores. However the small number of children precludes an inferential statistical analysis of the change in scores, as do problems associated with using Vineland standard scores to test for the significance of change (Williams et al., 2006).

The five children whose standard scores are reported in Table 15 for the third annual reevaluation represent those who participated in the KAW for longest period of time and were administered the initial evaluation and the three subsequent reevaluations. Interestingly, the potential number of children who might have participated in the third annual reevaluation was 25. However, at the point that these children were eligible for the third annual reevaluation, only the children whose families had requested an additional year of service were assessed.

Therefore, only 11 children were assessed and the other 14 children either exited the KAW early

or did not request an additional year of service and, thus, were not assessed. Of the 11 children who children did receive the third annual reevaluation only five of these children's standard scores met criteria to remain in the data pool.

Table 16 displays the scores of the nine children (identified by the letters A through I) whose scores on the reevaluations of the Vineland were removed from the analyses due to likely scoring errors.

Table 16

Vineland II Adaptive Behavior Composite Standard Scores of Children Removed From KAW Assessment Analyses Due to Scoring Errors: 1/1/08 – 11/30/10

Assessment Administration Results				
Child	Initial EVAL SS	1 st RE-EVAL SS ^a	2 nd RE-EVAL. SS ^b	3 rd RE-EVAL. SS ^c
A ^{ab}	70	47	20	NG
B ^a	78	63	56	NG
Ca ^b	65	49	47	NG
Da ^{ac}	53	20	60	37
E ^c	69	72	53	65
F ^c	74	63	61	45
G ^c	51	46	48	20
H ^c	52	54	61	20
I ^c	69	63	65	33

Note. KAW = Kansas Autism Waiver; EVAL – Evaluation; RE-EVAL = Reevaluation; SS = Standard Score. NG =Not Given

^a Standard scores on the Vineland Adaptive Behavior Scale II have mean of 100 and standard deviation of 15); ^b= dropped from analysis of first annual reevaluation due score outside the range of expected scores; ^c= dropped from analysis of second reevaluation due to score outside the range of expected scores; ^d= dropped from analysis of third reevaluation due to score outside the range of expected scores

Table 16 displays the scores that were removed from analysis if a child's standard score dropped to 20 or if a child's standard score represented a drop of more than one standard deviation in single year. A standard score of 20 is significantly below the expected range for children participating in the KAW and would indicate that a child with an obtained standard

score of 20 had lost almost all of their functional capacity, which, in fact did not occur. Hence, scores of 20 or a score that dropped more than a standard deviation within one year were accounted for as scoring errors. A drop of a standard deviation within one year illustrates an issue with the scoring, especially when looking at the follow-up scores where those children regained those losses.

Child D's standard score drops are particularly interesting. The first standard score drops significantly in the first reevaluation, then is regained on the second reevaluation and then drops significantly again for the third reevaluation. This type of pattern indicates errors in the administration, reporting or the scoring of this assessment.

An inspection of each of the children's scores consistently reveals unusual drops in their composite standard score means. If one or more of the errors were associated incorrect administration of the Vineland or because the procedures for scoring were not understood, the process of training individuals to administer the Vineland could be the source of error.

In the cases of Child A, Child G and Child H, each received a standard score of 20 on the last administration of the Vineland. Each of these cases represents an enormous drop in functional capacity that did not occur during this time period and, therefore, indicates an administration, reporting and/or scoring error. More specifically this kind of drop on the last assessment may indicate an attempt to report about the child and/or score in such a manner that a child could remain in the waiver.

Table 17 presents summary data of the number of children whose scores changed either in a positive or negative direction within one or more standard deviations.

Table 17

Direction of Standard Deviation Changes in the Vineland II Adaptive Behavior Composite Standard Scores of Children Participating in the KAW: 1/1/08 – 11/30/10

Assessment Interval	N of Child			n of Child		
	Positive Changes			Negative Changes		
	0-15 ^a (1 SD)	16-29 (2 SD)	30+ (3 SD)	-1-15 (1 SD)	-16-29 (2 SD)	-30+ (3 SD)
Beginning of 1 st year to end of first year (n=50)	26	1	0	19	3	1
Beginning of 1 st year to end of second year (n=38)	18	2	1	12	4	1
Beginning of 1 st year to end of third year (n=11)	4	0	1	0	3	3

Note: KAW = Kansas Autism Waiver.

^a Standard scores on the Vineland Adaptive Behavior Scale II have a mean of 100 and a standard deviation of 15.

An inspection of Table 17 shows that slightly more than 50% other children made gains in the composite standard score for the first two annual assessment intervals. Five of the 11 children made gains in the composite standard score for the third annual assessment interval. These results seem aligned with literature that indicates that early intensive intervention provides positive outcomes in approximately 50% of young children with autism diagnoses (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Sallows, & Graupner, 2005).

Remember that the standard scores of the children whose scores decreased by more than a standard deviation were viewed as likely to be scoring errors. The children with these scores were removed from subsequent analyses of these data and as display in Table 17 included four from the first assessment interval, five from the second assessment interval and six from the third assessment interval.

Research Question 4

Is there a relationship between changes in Vineland Adaptive Behavior Scale II annual scores of the children served on the Kansas Autism Waiver and the number of hours KAW services provided? Pearson product-moment correlation coefficients were computed to assess the relationship between the children's average number of monthly service hours and the change from their initial Vineland Adaptive Behavior Composite standard score to the standard score obtained on each of the annual reevaluations of the Vineland during their participation in the KAW. Correlations were computed to determine the relationship between the average monthly service hours with the standard score changes from the initial standard scores to: (a) the standard scores for the first annual reevaluation and (b) the standard score for the second annual reevaluation. Due to the small number of children available for analysis of the monthly service hours and the standard scores for the third annual reevaluation, a correlational analysis was not conducted.

The scores of four children that were considered possible scoring errors also were removed from the Pearson- product moment analysis pertaining to the standard scores changes on the first year's annual reevaluations. Thus, this Pearson-product moment correlation analysis was conducted with an n of 46 children and the obtained $r = .23$ was very weak and the probability of $p = .062$ fell below the significance level of $p = .01$.

The standard scores of five children that were considered scoring errors were removed from the Pearson- product moment analysis pertaining to the standard scores changes on the second year's annual reevaluations. The Pearson-product moment correlation coefficient analysis was computed for 33 children to assess the relationship between their average number of service hours per month and the change in their Vineland standard scores. A stronger obtained

correlation coefficient was obtained, $r = -.421$, and the probability was $p = .007$. The negative correlation indicates that as service hours increased, the Vineland Adaptive Behavior Composite Standard Scores decreased. It is important to note that a correlation should not be considered a causal relationship. Finally, while the correlation exceeded the probability level of .01 statistically, the value of the correlation is not viewed as indicative of a strong relationship.

As indicated, because of the small number of children (5) available after the standard scores of six children were removed due to possible scoring errors. The Pearson- product moment analysis to assess the relationship between their average number of service hours per month and the change in Vineland standard scores in the third annual reevaluation was not conducted.

Chapter 5

Qualitative Results

This study also employed qualitative methods to understand the perspectives of key stakeholders regarding the current status of the Kansas Autism Waiver and to provide insight into the quantitative results. The qualitative results reported in this chapter pertain to the data collected in the individual semi-structured open-ended interviews and focus groups. Questions were guided by the fifth and sixth research questions and participants were asked to share information regarding their experience with the waiver during the initial three years of implementation. Appendix D contains the questions that were posed to parent and professional participants in the interviews and Appendix E contains the questions that were posed to the professional participants in the focus groups.

Research Question 5: What factors do parents and professionals perceive as impacting the implementation of the Kansas Autism Waiver (KAW)?

Participants talked about a number of factors that either impacted or impeded the capacity of the autism waiver system to provide the needed resources and to implement procedures based on policies that resulted in effective implementation. Three themes emerged from the qualitative data that address the fifth research question. The dominant and first theme addresses the critical nature of the availability of the individual intensive support providers (IIS) and concerns with factors that impede this service. The second theme addresses several of the activities and procedures that shape the delivery of waiver services and are viewed as central to its successful implementation. The third theme addresses procedures and policies that support access to and navigation of the waiver system.

It all goes back to the providers: Intensive Individual Supports Services (IIS) and barriers to accessing these services. As noted, both the parents and the professionals viewed

the role of the intensive individual support providers (IIS) as critical. Intensive individual support services are provided by individuals who are assigned to work directly with a child in the home and/or community for up to 25 hours per week. These providers implement the goals of the child's Individual Behavior Plan using evidenced-based practices and document the child's progress on the goals in each of the domains that are selected from 12 domains. Their data is then shared with the Autism Specialist at the next visit and during team meetings so that progress is monitored and program revisions can be made as needed. A parent reflected on the value of this service when explaining that the success of the waiver "all goes back to the providers."

There was a consensus among the parents and providers that having an insufficient number of individual intensive support providers was a problem across the state. Concerns were expressed about the difficulties encountered when trying to find and hire providers for in-home services.

Parents found it particularly troublesome to know that their children were eligible for this kind of support, which they believed was critically needed, only to find that these providers were not available. A mother, while acknowledging that it is wonderful to have the waiver, emphasized that if quality intensive individual support providers were not available to implement the child's plan, the purpose of the waiver was negated. She explained how hard it is "when you find out you [can] have 25 [weekly] hours but there are not enough people out there [to provide support]." An Autism Specialist echoed her sentiment in describing challenges encountered when the waiver was first implemented, "Right at first there was a huge gap because there just plain weren't individual support providers out there . . . and so I did have complaints from people that 'we got on the waiver but then we waited a year or four months or something before we got any' [support]!"

Participants identified a number of factors that they perceived as influencing the availability of intensive individual support providers. These factors included the rural nature of much of KS and the related travel that was required of providers, the extensive and unreimbursed state training, the demanding requirements for IIS providers, the lower pay rate, the temporary nature of the career path of IIS providers, and the timing of the needed in-home and community services.

Rural geography of Kansas and related travel. Although participants from all areas of the state expressed difficulty in finding the needed number of intensive support providers, it was a much greater problem for those from rural, less populated regions. Only 45 children statewide may receive services at any one time on the waiver. While the residences' of the applicants vary, the largest concentration come from the KC Metro, Northeast, and Wichita regions of the state and are thus concentrated in urban settings. Several Autism Specialists believed that the smaller number of children served by the waiver in rural areas impacts the provision of services in these areas. A child located in a rural county is likely to be the only child served in the county and there may be no other children receiving waiver services in any of the nearby counties.

An obvious issue is that there are fewer qualified IIS providers in sparsely populated regions. An additional and significant issue is related to the costs of travel in rural areas. Mileage and travel time are considered to be included in the reimbursement rate for the various types of KAW providers and, therefore, agencies who are eligible to receive Medicaid reimbursement and enter into a contract to provide KAW service providers do not get mileage reimbursement or reimbursement for time spent traveling for the waiver that can be passed on to their providers. Thus, the payment rate for intensive individual support providers is the same

whether the child is located 5 minutes, 45 minutes or 5 hours from the provider's community of residence. This obviously creates more expenses for providers who are serving children in rural area that require considerable travel.

A few agencies that employ individuals who serve as intensive individual support providers also pay mileage, but then withhold some of the funds received for employee's service hours to compensate for the agency's payment of travel costs. This means the providers will be paid less of the full hourly billable rate while also receiving some funds that are specified as travel reimbursement.

The relationship between a limited availability of intensive individual support providers in the rural areas and the KAW's travel reimbursement policy are reflected by a comment from a quality management specialist, "My rural counties have greater difficulty . . . there are just no (intensive individual support) providers and the closest provider is 30 miles away and they just won't travel with not being able to pay for travel time . . . we have only had that problem with intensive individual care specialists (IIS), [not wanting to travel] the autism specialists are very willing to come out." (It should be noted that the Medicaid reimbursement rate for the autism specialist is considerably higher than for the Intensive Individual Support providers).

An autism specialist explained, "it's very hard for an autism specialist to find intensive individual support people who will drive, you know, in our case, sixty miles round trip to see a kid and not get mileage for it." Three of six parents explained that while they had found intensive individual support providers that traveled to their rural locations from other cities, these providers had eventually discontinued their services due to the cost and inconvenience of travel.

An autism specialist who was led a waiver team comprised of employees that also worked for her agency (which was an agency that did reimburse employees for their mileage in

addition to time spent working with children) pointed out that the large distances that were involved when working in rural communities influenced the amount of community involvement that an intensive individual support provider could provide for a child, “Our kids that are way out [geographically], we can’t always take them where we want to take them because of pay once again, and because of mileage reimbursement. I’m ending up spending more money sending a person out to (the child’s) house and (also) picking them (the child) up and taking them to that place (in the community) than I (the agency) am getting reimbursed for.”

Extensive and unreimbursed state training. Participants discussed the training that is required of those who provide waiver services. While some inconveniences were experienced by other professionals representing the various KAW services, the much more extensive training requirements for the intensive individual support providers impacted their availability to provide services on the waiver. Specifically, training requirements for intensive individual support providers (IIS) include completing an online training and then participating in six full days of onsite training, which has a lecture component as well as a component that requires individual practice with children with autism in clinical settings and in a child’s natural environment.

Additional issues that emerged as associated with the training required of the intensive individual support providers included the limited availability of training slots per training cycle and the lack of state reimbursement for participation in the training.

The limited number of slots available during each training session means that an individual who wants to serve as a provider often does not have the opportunity to participate in the required training session because none of the sessions are a good fit with his/her schedule. An IIS provider explained that this often delayed the completion of the required training and

thus, the point at which an individual could actually serve as a provider. Several parents talked about their frustration with knowing about individuals who wanted to be providers but were waiting to be trained. As one of these parents stated, “without a trained person you can’t implement the program, the plan doesn’t work.”

Several professionals explained that while the state-approved training is provided free of cost, the agencies incur expenses for agency employed providers to participate. While employed individuals must be paid, they are not producing billable hours during the required training period. Thus, as one of the autism specialists commented, the “cost of sending providers to the training is detrimental.” Another autism specialist shared that her agency “pay[s] for their time while they are at the training,” another stated that her agency had found a way to avoid these training costs by telling potential providers “have everything [completed] before you even come in the door [before being hired].” Thus, by requiring individuals to complete the KAW required training before hiring them, this agency does not have to pay salary or travel costs to the individual while they attend the training. An intensive individual support provider highlighted a problem with this strategy from her perspective by pointing out that attending the training meant that she was required to go for “a whole week [without] getting paid.”

Demanding requirements for IIS providers. Both the parents and professional participants talked about problems involved with attracting individuals who were qualified to work in the intensive individual specialist positions and also in retaining these individuals in the IIS position. A parent explained that when she attempted to recruit providers (i.e. IIS) through community agencies and other parents, “a lot of people told me that [the] requirements were too hard . . . that they didn’t have anybody who could meet those requirements.”

For some participants, the 1,000 hours of experience was the most difficult aspect of these criteria and as the director of one of the agencies that service the waiver put it, “[it is] hard to find people who have the 1000 hours of experience!” For others, it appeared that the hours of college credit in addition to the experience requirement was insurmountable. Another agency director explained that, “to find a Bachelor level IIS worker can be very challenging, particularly, [one] that’s had the thousand hours of documented experience.”

Inadequate reimbursement. This view about the unrealistic requirements is strengthened by the perception that the pay rate of intensive individual support providers is not commensurate with the required experience and education expected for their role in the waiver. It is preferred that an intensive individual support service hold a bachelor’s degree, but must have a minimum of 60 hours of college credit as well as 1,000 hours of experience working with individuals with autism.

Both parents and professionals expressed frustration with the compensation for KAW service providers. While a few concerns were raised in relation to the reimbursement rates for respite care providers and autism specialists, the majority of these comments addressed the compensation of IIS providers. An individual who worked as both an intensive individual support provider and a respite care worker explained that to make a living she works “full-time with one agency and part-time with another.”

The income of intensive individual support providers is also impacted, as explained by an autism specialist, because they can “only be paid when they are with the child.” This issue was addressed by parents and providers and both emphasized that the direct hours an intensive individual support provider spends working with a child do not represent all of the hours that go into providing quality services to a child. Additional hours have to be directed to material

preparation, data collection, summarization, and analysis, as well as team collaboration.

Unfortunately, none of these additional hours are reimbursable.

Another issue that was raised by many of the participants related to provider reimbursement is that the “waiver does not allow all the providers to be at the house at the same time.” Both parents and professionals pointed out that the KAW regulation of only reimbursing one provider at a time has presented difficulties in creating collaboration opportunities such as the required team meetings. When a child’s team meets, only one provider can be reimbursed for their time, and the other members of the team (who are KAW providers) cannot be reimbursed. While this obviously impacts all providers, once again, the individual intensive support professionals are significantly impacted. Their participation is critical to team meetings as they are the providers who are implementing the child’s goals and also the providers with the lowest pay rate with the exception of respite care workers.

Essentially, participants believed there are a limited number of individuals who meet the criteria of experience and education and would choose to become an IIS worker. And if they do meet the criteria, they already have a full time job and/or are on a different, but related, career path.

Temporary nature of the role. One of the factors perceived to be related to the problem of finding and then retraining intensive individual support providers was the lack of advancement or progression within this position. Professionals discussed the interim nature of the IIS position indicating that the individuals in this position eventually move to higher-level jobs and that most intensive individual support providers regard the job as a temporary step on the path to their chosen career. For example, one of the intensive individual support providers said that while she “would remain in the autism field,” she planned to transition into a role of

administrator or consultant. Another shared that, “my plan is to eventually be an autism specialist,” which is a KAW position with a higher pay rate. A parent explained that her IIS providers were “definitely [in] transition,” with some “going to school in a related field,” and several others “in addition to their [IIS] work, hav[ing] [another] full time job.”

Parents reported that college students or individuals with other “full-time jobs” were serving as their children’s in-home providers and that the “students are going to school in a related field.” They also expressed a desire to have IIS workers who are “out of school [and] who want to do this [IIS work] more consistent [ly].” This transitory nature of providers appeared to be an issue across the state, with many viewing their work as an intensive individual support provider as a way to gain experience that will benefit them in their chosen career paths. Parents reported that college students or individuals with other “full-time jobs” were serving as their children’s as in-home providers and that the “students are going to school in a related field.”

Inconvenient timing of needed IIS services. Both parents and participants considered the times that children were available to receive the services of an intensive individual support provider to contribute their limited availability. Participants explained the services of the intensive individual support providers were most frequently requested for the after school period (i.e. late afternoons and early evenings) and for weekends. This is because many of the children receive early childhood or early elementary public school special education services and not available to use the waiver services until their school day is over. An Autism Specialist commented that it “can be tricky to match kids’ schedules with staff availability.

The above situation also contributes to the fact that the intensive individual support providers often only work part time as IIS providers and are also students or have another full-

time job. One of the intensive individual support providers shared that she had to work for several agencies and worked seven days a week in order to get enough hours to make a living and noted that she had worked with “over 12 children since the waiver started and was balancing four children currently to make up enough hours.”

Participants identified a number of factors they perceived to facilitate the effective implementation of the KAW. These included the required state training for KAW providers and the support provided to assist parents and providers in navigating the complex Medicaid and KAW systems.

A cohesive picture is the goal: KAW procedures impacting implementation. The second theme addresses several of the activities and procedures that shape the delivery of waiver services and are viewed as central to its successful implementation. These include the participants’ perspectives on the impact of the required provider training, the importance of a collaborative team approach, and the necessary but problematic eligibility determination process.

Impact of the required provider training. The value of the requirement that all KAW providers attend approved waiver training was voiced by many of the participants. An intensive individual support (IIS) provider described the benefits of the training as bringing “all the pieces of the waiver together into a cohesive picture. And of course working as a cohesive picture is the goal.”

A parent explained how the training had made a positive impact on her child’s IIS provider who had limited experience with children with autism.

For people with minimal experience [the training] shows them some ways to take data and such. One example, once she [a novice provider] went through the training, I noticed that before [the training] she fell for him [the child] cuddling her to escape [from

demands], but now [after training] she quickly got him back to [therapy]. [For] some providers it is more refinement of their skills. It really depends on how much they had experience before.

Other parents also talked about their awareness of the positive changes they had seen in the their children's IIS providers' skills after the training. For example, a mother commented that since her child's providers had attended the training she had seen a "gradual increase in their skill level." She also shared her perspective that the training had seemed to make it "it all come together - the understanding of why'" (i.e. why related to why specific strategies are chosen, why data is collected, etc.)."

Importance of a collaborative team approach. The participants' perspectives saw the use of a collaborative team approach that multiple team members who bring a range of differing expertise to table is critical to the implementation of goals and intervention strategies.

Both autism specialists and parents emphasized the value of parental input, particularly in identifying and prioritizing goals. One of the parents talked about how she became a more active team member over time. She noted that in the early team meetings her role was fairly limited but that she "helped when I was asked to give input." However, once she became familiar with the team process she shared that she became an active and involved team member. Several parents also talked about how their participation in meetings was an important component because they participate while group reviews the programs, identifies what is working and what needs to be altered to improve the effectiveness of their child's program and this allows them to implement what it working in the other times of their child's day and ensure that their goal priorities are included.

Professionals and parents all agreed on the importance of ongoing data collection to ensure that a child's progress on their goals is documented. Finally, because most of the waiver services are provided in the home, several Autism Specialists and agency providers shared that parents are in a unique position to monitor the delivery of services to the child and thus can contribute to the implementation fidelity of intervention procedures. This is, in part, because parents are present on a daily basis, whereas the autism specialist or other agency providers are not. And, of course, parents have a uniquely personal investment in advocating for the quality of the services a child is receiving.

Eligibility determination: Necessary but problematic. As part of the initial eligibility process, each child was assessed with the Vineland Adaptive Behavior Scale II (VABS II) and was required to meet certain score levels to be eligible. The VABS II is also administered in the annual re-evaluation and certain score levels are also required to maintain eligibility. Although the participants' discussion of the eligibility process and the administration of the VABS II predominantly raised concerns with the validity of the assessment process, several participants had favorable comments.

Both parents and professionals recognized the importance of the eligibility process, and both indicated that they understood the necessity of an assessment as part of the process and the comprehensive nature of the assessment was viewed favorably. A parent explained that having to answer questions across multiple areas helped to give her a "complete picture" of the skills that might be expected of her child. Several other parents and providers also commented that the value of the breadth of questions and how they assisted them to gain insight into the needs of a child. However, the majority of the participants' discussion of eligibility process was directed to their concerns with the VABS II assessment. The remainder of this section focuses on

participants' concerns with the VABS II assessment, with parents' presented first and the professional's next.

Parent concerns with the VABSII assessment process. When the parents described their experience with the VABS II, several noted that the assessor started by explaining that the test would determine the waiver eligibility of their child, which sometimes created a sense of anxiety about the process. Some parents suggested that the intrusiveness of the questions was balanced by the fact that if their child qualified for the waiver it would be beneficial for them. Several parents also complained that there were too many questions that they had to answer "on the spot", without sufficient time to think the answer through.

Problems with the clarity of the questions and the response options that were allowed for the questions were also mentioned. Several parents talked about the difficulty they experienced in answering a question about a behavior of their child by choosing "usually, sometimes, or never." Parents indicated that they found this difficult because their child's behaviors were not consistent. One of the parents explained that her son's behaviors had "holes in it" and that he might demonstrate a behavior "on Monday but not on Tuesday." Essentially, some parents would have preferred to describe their child's behavior instead having to choose a single term such as 'sometimes' or 'never'.

Professionals' concern with the VABSII assessment process. Professionals also raised concerns with both the validity of the VABS II and the administration process. A quality management specialist voiced their concern about the parent report format:

[When a child is] assessed, you have a couple of different things you can't control regarding the parents' emotions at the time. They'll either report the child is doing extremely well, because, one, they don't want to be embarrassed by how they feel their

child's performing or, number two, they may be concerned that SRS is going to come take their child away because the child's not doing well. So, those are just a couple of examples. And then they may over exaggerate their child's disabilities so that they can retain eligibility. So, I think it's a very easily skewed instrument, because it is self-report by the parent who, obviously, has a vested interest.

The professionals also raised questions about parents' ability to be familiar with all of the activities addressed by the questions in the VABS II. One of the autism specialists pointed out, "the parent does not always see what the child can do."

Several autism specialists and agency professionals recommended that providers attend the VABS II assessment meeting with the family, even though the VABS II administration is designed as an interview format with one reporter, the parent. These professionals believed that provider participation would allow for clarification and enhance parents' responses about their child's behavior in various activities and settings.

Other autism specialists pointed out that having providers participate in the assessment could be problematic because who attended and what they said could vary significantly across the annual administrations. For example, during the initial assessment, the families are not yet working with waiver providers. During the annual VABS II re-evaluations a provider may or may not be able to attend or may have limited experience with the child depending upon how long he or she has worked with a child. And, the specific providers assigned to a child can vary from year to year.

Navigating the waiver: challenges and resources. Comments of the interview participants and the focus groups frequently pertained to the challenges of navigating the Medicaid system in general and the Kansas Autism Waiver in particular. Parents explained that

they “didn’t know where to turn” when their child first became a recipient of the KAW and that they frequently felt “stressed” during this period. Providers talked about feeling “overwhelmed” with some of the waiver requirements.

Four factors were identified as important to both parents’ and providers’ ability to navigate through waiver process. These include the accessibility of the program manager, support from the contracting agencies’, coordination of waiver services with other services such as Developmental Disability (DD) services, the role of the autism specialists as team leaders, and the information sharing that occurred due to the Autism Steering Committee.

KAW program manager. The KAW program manager is the individual who is tasked with the overall management and oversight of the waiver within the KS Department of Social Rehabilitation Services. All of the parents described her as “really helpful.” For example, she assisted with the identification of supports by sending a list of enrolled providers and responding to their questions whenever she was contacted. One of the parents described a time when the program manager came to her rural area of the state and personally “presented [her with] waiver information” and then assisted her in identifying providers.

The majority of professionals described the program manager as “always very approachable and easy to talk to.” For example, an agency director talked about how the program manager helped her to deal with her frustrations over paperwork, “[She helped me] to calm me down, to keep me going, to remind me all the time, it’s the kids, it’s not the paperwork hassle.” As an autism specialist put it, “it’s fantastic to have a supportive SRS Manager who is available to answer your questions, to give you direction, [and] to give you guidance.”

The role of the agencies that contracted with SRS to provide KAW services was also addressed in the discussion of helpful resources for navigating waiver services. The

professionals who served as providers across the range of KAW roles expressed frustration with the enrollment process required to become a KAW provider which they found to be confusing and foreign to their previous experiences with applications. The process includes filling out an extensive packet of paperwork, the submission of a number of required documents, and the completion of five background checks.

Providers comments about the valuable support provided by their agencies in dealing with the “huge packet” of paperwork required for provider enrollment and billing for services required by the waiver. An agency director who oversees the enrollment and assignment of autism specialists and intensive individual support specialists commented somewhat sarcastically that this had been a “learning process” that included being educated about the required color of pen needed for the parts of the application and that “the whole thing gets returned to you” (if you) sign in the wrong place or with a black pen.” One of the IIS providers shared that she felt “overwhelmed by the paperwork” but that the agency had “just handled it all.”

Parents also talked about the support provided by the agency in their region. The majority talked about the value agency staff assisting them by identifying providers for their child. One the parent commented that “[I] get a list of people from the agency and they come out and play with my child and I choose to keep them or let them go.”

Additionally, according to the parents, the agency in their regions sometimes assisted them in applying for waiver services.

Coordination with other Medicaid waivers. Targeted case management is a service available to children who are Medicaid eligible and meet the eligibility criteria for the DD (Developmental Disabilities) or the SED (Severely Emotionally Disturbed) Medicaid HCBS

Waivers in Kansas. These waivers are separate from the KAW, but can offer complimentary services that are available to children served in the KAW.

According to KS Department of Social and Rehabilitation Services, targeted case management (TCM) is a service that is designed to “assist the individual in accessing necessary medical, educational, social, and other needed services” (Targeted Case Management, n.d.).

Discussion among the steering committee members centered around TCM as an under-utilized resource. It was noted that many professionals are unaware of the availability of TCM for children in the KAW, and that, while the role of an Autism Specialist is to facilitate the child’s services within the Autism Waiver, targeted case management for additional services can be provided by a DD case manager (Developmental Disabilities Waiver) or Mental Health case manager (Severely Emotionally Disturbed Waiver). This addition of case management for an additional waiver allows for more support across a child’s environments. An Autism Specialist pointed out that the “the Autism Specialist can get drawn into a lot of social service-type aspects with the family unless the family has a DD [Developmental Disabilities Case Manager].”

Participants concurred that families often have needs Medicaid services that are not part of the KAW. They also recognized the importance of collaboration across the various services would be critical and unanimously agreed with an agency directors statement that, “the marriage between those two systems [i.e. Autism Waiver & DD waiver] has been good and I think it has allowed the autism specialist to focus much more tightly on that child and their needs.”

Participants also emphasized the importance of ensuring that lines were clear regarding the role of the autism specialist and the DD or MH case manager in order to avoid the duplication of services.

Autism specialists as the team leaders. Parents all highlighted the importance of the role of the autism specialist (AS) as the facilitator of their child's teams. One parent shared that she was:

Very happy with the AS and the way she is able to manage our team [the IIS workers] . . . she is positive, organized. She has a lot of attributes that help our team of people be professional, keep up with their skills, keep us efficient, keep us on track. Her management of the whole program is what is making everything so successful. She has great experience and knowledge. Without having an AS with skills in all those areas, we would not be where we are today.

Another parent commented that her autism specialist "will walk me through anything. [It is] nice to know someone is over [my child's] program getting my son to the direction he needs." These two examples echo the comments by the other parents' view of their autism specialist and her or his role in setting expectations, facilitating the team and leading the providers and the family through the waiver process.

Role of the steering committee. Members of the group believed that the role of the Autism Steering Committee is important and talked about the value of having a representative group of professionals and parents that meets on a regular basis to discuss issues and problems as they arise and to brainstorm solutions to ensure the waiver runs smoothly. Professionals recognized the somewhat circuitous nature of the steering committee, since its members are charged with planning and oversight of the waiver, while the majority of the members are also involved in implementing the waiver. One example that was offered by a quality assurance (QA) professional was that her role as a representative on the steering committee enabled her to share her increased understanding of the waiver with the other QA professionals in the field.

Several professionals who were past members of the steering committee member commented on the value of their participation. For example, an autism specialist who had previously been a part of the steering committee believed she had “learned from being part of this committee” and that the acquired information was “really, really beneficial”, because she could share it with others in her agency. The fact that steering committee members are able to relay accurate information to providers in the field was perceived to be an important factor in facilitating navigation of the waiver process for providers and, subsequently, for families.

Research Question 6: What are the perceptions of parents and professionals regarding the outcomes for recipients of the Kansas Autism Waiver?

When asked to talk about the outcomes for the KAW recipients, comments were extensive and enthusiastic. Outcomes were identified for families as well as for the children receiving waiver services. Interestingly, not a single participant identified a negative or disappointing outcome.

The waiver that seems to win all the time. Comments about the waiver outcomes included very positive descriptions of the providers and services, such described having a child participate in the waiver as “like winning the lottery,” another reported being “95% satisfied,” and others used terms like “delighted,” and “grateful.” A mother summed up her sentiments by explaining that, “my child has made progress and undoubtedly it is due to the services provided through the waiver.” And, another parent enthusiastically stated that the positive impact of the waiver involved “too many changes to relate.” More specifically, participants provided examples of the types of outcomes they experienced and valued. These included opportunities for the child and family to be included in the community, increased child safety, improved interaction and social skills development, and gains in language development.

Community inclusion for the child and family. Participants were unanimous in the belief that these positive outcomes enabled the children to participate in community activities. A few of these activities shared by parents included, “participation in a latchkey program at the local church,” participation in “gymnastics classes,” and “going to the grocery store.” One parent talked about her child as no longer being distinguishable from his peers and noted that, “[other] parents don’t know he is on the spectrum.” Several autism specialists offered examples of children as “no longer qualifying” and being “fully integrated with their peers in school,” largely as a result of waiver services. Another parent’s explained that that the waiver: “greatly affected our overall family in positive way. I would say that just this past summer 2010, we were able to go out to restaurant, to the fair, [do] more family type things.”

Several of the intensive individual support professionals and autism specialists pointed out that many families of the children did not go anywhere before the waiver services began. As one of the parents put it, they “couldn’t take their child anywhere.” Now, according to another parent, her family can go “basically anywhere in the community.”

Increased child safety. Several parents talked about positive changes that resulted in their child’s ability to be safer in their homes and communities. These parents described the significant difficulty they had experienced prior to receiving waiver services in keeping their children safe due to their behavioral challenges. One talked about how she had “two child gates stacked on top of each other” just to keep her child safely in his room and that he was “still climbing over those!” Another parent stated that her child “literally climbed the walls.” According to these parents, both of these children now play safely in their homes and stay in their rooms at night.

A child's increased safety awareness and development of the related behaviors also led to increased opportunities for several families to participate in community activities. Several families and providers indicated that the waiver services enabled young children to safely be around water. This was made possible because access to the waiver allowed the children to have the needed support to participate in swim lessons. One of the parents explained that, prior to the waiver, even though her child could not swim he would just "jump in the pool." An agency director related that "another child [with autism in their region of the state] drowned this summer", and then emphasized how important swim lessons are to these children. She also shared that, because of this drowning incident, another "family [with a child served by the waiver] and [their] autism specialist" were "adamant the child learn to swim." She proudly announced that "now he can swim!"

Traffic dangers were also a topic that came up during discussions of safety. For example, a parent described how her child would "dart out in front of a car." An intensive individual support provider happily shared that after working on this safety issue for month, a child demonstrated an understanding of street safety when upon observing a dead squirrel in the middle of a street, the child said, "the squirrel forgot to look both ways."

Increased interaction and social skills. Participants unanimously discussed changes in the child's ability to interact with adults and other children. Examples of settings and situations in which a child's improved interaction and social skills made a difference included participation in catechism, going to the dentist, participating in boy scouts and in girl scouts, and learning how to play soccer. An agency director proudly shared an example that one of the IIS provider from her agency had shared with her about a child who learned how to shop at the convenience store and how he just "picked out the item, [and] handed over the money."

Parents happily talked about how their children were connecting with the peers in school. For example one parent explained that her child was “connecting with peers, looking at them, waving.” One parent shared that her child was “closed off to everyone but through the waiver they’ve been able to open up and talk to others.” Both the autism specialists and intensive individual support providers believed that the waiver had “dramatically impact[ed] the children’s access to peers.” There comments included descriptions of children’s accomplishments such as how a child learned how to “play a game for 20 minutes” or how another was beginning to participate in “recess activities.” One of the IIS providers shared talked about a child who could now “play video games with his siblings and friends who come over” as well as the big changes that were being reported from school and “about how he interacts with peers and they like him.”

Improved language development. Participants also talked about the increased language and communication skills the children had acquired since participating in the waiver and they emphasized the importance this area. As one autism specialist exclaimed, “language is huge for these kids!” Stories of dramatic changes in communication were shared. For example, a parent reported that, initially, her child was “basically echolalic” and had “only 8 words when we started [waiver services]”, but that now he, “can have conversations!”

Overall all of the participants, both parents and professionals were extremely complimentary of the waiver and the progress for the children and family served. Parents specifically addressed the overall impact of the waiver services on their families.

There was consensus among the participant of the interview and focus group on the majority of issues within the waiver. Interestingly, the comments on the challenges to obtaining intensive individual support providers were primarily offered by parents, autism specialist and specific agency participants and not from the intensive individual support providers themselves.

This may be because the parents, autism specialists and agency directors were the individuals who directly experienced the challenges of locating intensive individual support providers.

In conclusion while waiver problems and issues were identified and discussed the participants clearly related the perspective that the KAW is making an impact across the state. This perspective is reflected in the statement of a quality management specialist, “This is the only waiver where it has been universally appreciated and universally successful. The amount of success is at different degrees, of course, but still successful. It is the one seems to that wins all the time.”

Chapter 6

Discussion

This dissertation study employed a mixed method approach to the investigation and analysis of the implementation of the first three years (i.e. 1/1/08 – 11/30/10) of the Kansas Autism Waiver. Hopefully, the results of the study provide useful information for policy makers, administrators, providers, and families who seek to improve this waiver or improve or develop and implement another HCBS waiver for children with ASD.

A mixed method is often used in highly practical contexts that require pragmatic recommendations using limited funds to solve complex social problems (Greene, 2007). Evaluative data are gathered in practical ways using both quantitative and qualitative methods that are functional and pragmatic (Patton, 2008, 2011). A mixed methods approach is of particular value in situations where triangulation across forms of data is needed to strengthen the validity of the results of a study or to offset potential limitations of any one particular set of data (Greene, 2008). Hussein (2009) defined triangulation as the use of multiple methods, mainly qualitative and quantitative methods, in studying the same phenomenon for the purpose of increasing study credibility. This implies that triangulation is the combination of two or more methodological approaches, theoretical perspectives, data sources, investigators and analysis methods to study the same phenomenon.

This chapter initially reviews the study's results by briefly linking and summarizing the quantitative and qualitative findings through the lens of evidenced based practices that guided the development of the waiver. This is followed by a more extensive discussion that considers the implementation of the KAW through the lens of quality assurance components that should guide the evaluation of public programs such as the waiver. Both reveal corroborative and conflicting data that offer insight into the status of waiver's implementation. When relevant to

the findings directed to quality assurance components, other research that may offer insight into the results is presented and recommendations for the KAW policies and procedures are offered. The study's limitations are identified next and, finally, the chapter concludes with recommendations for future research.

KAW Implementation: Adherence to Evidence Based Practices

The identification and implementation of evidence-based interventions and outcome measures through comprehensive reviews of intervention studies that address ASD have recently become a focus across professional organizations and agencies associated with human services. The committee that developed and submitted the Kansas Autism Waiver was guided by evidence based research that was used to inform the waivers practices and procedures. Table 18 summarizes the waivers policies and practices, as well as the results of the qualitative and quantitative data collected in this study for the following four evidence based practices in treatment of young children with autism: Intervene Early, Intensive Intervention, Prolonged Duration, and Child Progress Measurement.

An inspection of Table 18 immediately reveals problems with the fidelity of the implementation of the evidence-based practices. It also offers a means of viewing the perspective or information related to implementation provided by the qualitative and quantitative procedures employed in this study.

A primary intent underlying the waiver is to intervene early, and preferably before age 4, is not being met. The quantitative data indicates that the means entry age is 4.49 years.

Table 18

*Relationship of Evidence-Based Practices for Young Children with ASD to the KAW Service**Policies & KAW Investigation's Qualitative and Quantitative Data Results*

Evidence-based Practice	KAW Policy / Procedures	Qualitative Results	Quantitative Results
Intervene Early (As soon as diagnosed, preferably before age 4)	Application for KAW can only be made for children under 6 years of age	Waiting list delayed age at which child could begin services “My child waited a year and a half to start after being selected”	Mean KAW entry age = 4.49 years old
Intensive Intervention (15 hours [minimum] to 30 hours per week)	25 hours per week of intensive individual support services	Hard to find and keep IIS providers “ . . . you [can] have 25 [weekly] hours but there are not enough people out there].”	Mean hours per week of IIS providers = 7 hours and 13 minutes
Prolonged Duration of Intervention (At least two years)	<ul style="list-style-type: none"> Services can be provided for 3 years - as long as eligibility is maintained. Can request 4th year. 	<ul style="list-style-type: none"> Waiting list impacted service duration. “My child waited a year and a half to start after being selected. 	Mean months of KAW services = 20.42 with SD = 9.87 months
Child Progress Measurement/ Outcome Assessment (Ongoing performance measurement on functional skills and documentation impact of the provided services)	<ul style="list-style-type: none"> Initial & annual eligibility assessment with the VABS-II. Team priorities and sets child goals & objectives IIS implements & documents the child's progress on IBP/POC goals and objectives 	<ul style="list-style-type: none"> Professionals questioned validity of VABS results “So, I think it's [VABS-II] a very easily skewed instrument, because it is self-report by the parent who, obviously, has a vested interest.” Participants valued ongoing data collection. Participants reported increased access to the community, improved child safety, interaction & social skills, language “My child has made progress and undoubtedly it is due to the services provided through the waiver.” ” 	<ul style="list-style-type: none"> Vineland standard scores did not show consistent improvement. IBP/POC data on specific skill areas were not obtained. Results of IBP/POC goal data were not obtained.

The qualitative data indicate that the failure to enroll and begin services for children under age 4 seems related to waiting lists for eligibility and waiting periods for services after eligibility has been established. The low number of children receiving services increases the wait time and results in increasingly large wait lists that exacerbate the age of the children at intake, which is in fact the current situation with the KAW.

A second intent of the waiver was to provide intensive intervention. The KAW's IIS services are provided by individuals who are charged with actually implementing the strategies to address most of a child's individual behavior plan and plan of care (IBP/POC) goals. The KAW allows for a child to receive 25 hours of IIS services per week. An inspection of Table 18 indicates a major discrepancy between the quantitative data results that reveal that mean hours per week of IIS providers is 7 hours and 13 minutes, which is significantly lower than 25 hours provided by the waiver. The qualitative data indicate that the waiver is experiencing problems with finding and maintaining IIS providers. This is an implementation concern that is related to the fidelity component related to the *dosage or exposure, which is analogous to the* amount of intervention that is delivered to participants, such as the duration or frequency of sessions that is delivered to participants is not meeting the intent of the procedure..

Another intent of the waiver was to provide a prolonged duration of the waiver of at least two years and each child is actually provided with three years their assessed eligibility is maintained and a 4th year of KAW services can be requested. The quantitative data indicate that this intent has not been met over the course of the KAWs implementation period and that the mean months of KAW services is 20.42 months with a SD = 9.87 months. The standard deviation suggests that although children are receiving slightly more than two years of services, as many are receiving around 1 year of services. Once again, the qualitative data indicates that

waiting list has impacted the duration of services. These results also raise concerns with dosage or exposure aspect of implementation fidelity and relates to measuring whether or not the amount of intervention that is delivered to participants is meeting the intent of the procedure. In this case, the limited duration of the services raised concerns about the waiver implementation.

A fourth intent of the waiver was to ensure that child progress are measured and outcomes be assessed. The quantitative data shows that while standard scores on the Vineland Adaptive Behavior Scale II (VABSII) (Sparrow, Cicchetti, & Balla, 2005, 2006, 2008) were collected and assessed relative to child outcomes, the results are not clear. Further, although individual performance data is collected, individual data was not obtained for this study and no summary data on the achievement of individual goals is available from the waiver. The qualitative data indicates that participants' value ongoing data collection and that they view the individual progress of children and thus the outcome of the waiver very favorably. In relation to this qualitative finding, it appears the participant responsiveness is high, which is a positive indicator of the implementation of the program. Conversely, participants expressed concerns about the validity of the scores obtained on the VABS-II. While this does not indicate a problem with participant responsiveness, this does indicate concerns with adherence, a key component of implementation fidelity, that pertains to whether intervention strategies are implemented as designed and to the adequacy of their training for personnel responsible for implementing program procedures.

KAW Implementation from a Quality Assurance Perspective

An increasing emphasis is placed on quality assurance efforts that report the outcome of services provided through state and federal funds. A national review, conducted by the Research and Training Center on Community Living, Institute on Community Integration (UCEDD) at the

University of Minnesota, studied the Medicaid Home and Community-Based Services “waiver” program during its first 20 years of implementation, from 1982 through 2002. The policy research brief of the review explained that because of the rapid growth in community services associated with programs such as the HCBS waivers, states had not been able to keep up with either the changing expectations regarding quality or the tremendous variety in locations and providers (Lakin & Prouty, 2003). This research brief also noted that when quality assurance measures had been taken, there were numerous examples of flaws including a continued emphasis on the process involved versus actual outcomes.

A much more recent national review of Home and Community Based Services (HCBS) for individuals with autism spectrum disorders, also conducted at the University of Minnesota’s Research and Training Center on Community Living (RTC) gathered data concerning the 13 HCBS autism waivers offered by states from 2009 to 2010. The policy research brief associated with this review concludes with a call for research that increases our understanding of the outcomes of state-specific programs as essential in informing future ASD policy development (Hall-Lande et al., 2012).

The present investigation of the Kansas Autism Waiver (KAW) was designed and implemented in response to the issues and needs addressed in the national policy briefs of the HCBS waiver programs just described (Hall-Lande et al., 2012; Lakin & Prouty, 2003). And while this investigation was not comprehensive, the essential components of a quality assurance analysis set forth in the booklet issued in 1999 by the President’s Committee on Mental Retardation (PCMR, 1999) (now referred to as the President’s Committee for People with Intellectual Disabilities) are included in Table 19. Specifically, Table 19 offers a side-by-side summary comparison of the quantitative and qualitative results for each of these areas and

therefore, shows areas of convergence among the quantitative and qualitative data.

The subsequent discussions each concern results summarized in Table 18 and are directed to four types of findings: (a) findings for which the quantitative and qualitative data converged to reveal both problems and strengths, (b) findings for which the quantitative and qualitative data results diverged in terms of the nature of the results, (c) findings concerning KAW strengths or concerns that were revealed by only one form of data (i.e. quantitative or qualitative), and (d) areas for which data needed for a complete quality assurance analyses are insufficient.

Table 19

Quality Assurance Areas and Related Study Results

QA Area	Study Results	
	Quantitative Results	Qualitative Results
Inputs Services, staff training, staff persons and other resources & strategies that are included in a program to ensure it can be implemented appropriately	Analyses compared each type of service provider's waiver allotted hours service hours with the service hours actually provided by each type of service provider	Participants' discussion indicated: <ul style="list-style-type: none"> • satisfaction with AS role • satisfaction with required staff training • concerns with IIS role <ul style="list-style-type: none"> ○ availability to participants ○ relationship between role requirements & pay
Process Compliance with regulations that describe exactly how a service is to be delivered.	<ul style="list-style-type: none"> • Some of the reported Vineland standard scores indicate errors in the scoring process. • Analyses compared each type of service provider's waiver allotted hours service hours with the service hours actually provided by each type of service provider 	Participants' discussion of <ul style="list-style-type: none"> • concerns with the eligibility assessment process. • impact of waiver policy of paying only one person at a time on team meeting attendance • effective management of child teams by ASs.
Impact Program impact on the greater society	Not measured by study and waiver procedures for data collection not in place	Not addressed in participant's discussions
Reactions of participants Satisfaction with the various aspects of a program	Not measured (failed survey due to very low percent of returns)	Participants' discussions indicated: <ul style="list-style-type: none"> • Satisfaction with <ul style="list-style-type: none"> ○ child outcomes, ○ roles of the AS ○ use of collaborative teams, ○ support by PM ○ role of steering committee • Concerns about <ul style="list-style-type: none"> ○ wait prior to service onset ○ availability of the IISs and the associated policies, ○ validity of the eligibility process ○ DD waiver coordination

Table 19 – continued

Quality Assurance Areas and Related Study Results

QA Areas	Study Results	
	Quantitative Results	Qualitative Results
Organizational effectiveness Degree to which a program's organization structure, policy, resources and fiscal procedures are adequate.	<ul style="list-style-type: none"> • Service hours and duration of waiver services do not correspond to recommendations based on review of effective practice literature. • Vineland Forms for annual re-assessment did not use recommended form for showing progress. 	<ul style="list-style-type: none"> • Participants' discussion indicated satisfaction with <ul style="list-style-type: none"> ○ support provided by Program Manager ○ role of the Steering Committee. • Concerns with <ul style="list-style-type: none"> ○ wait time between eligibility confirmation and the onset of services, ○ policies and pay for IIS providers, ○ impact of waiver policy of paying only one person at a time on team meetings
Data profiles created by Management Information Systems Use of computer-based systems to provide ongoing database that create profiles that improve the quality of organizational or system-wide decision making.	<ul style="list-style-type: none"> • Data used to create the child demographic and service usage data profile were obtained from the Automated Management Information System (AIMS) and service utilization data was obtained from the Medicaid Management Information System (MMIS) –both maintained by the KS SRS. 	Not addressed in participant's discussions
Quality of life Influence of the waiver on the recipients (child and family) ability to access items/activities/outcomes similar to individuals without disabilities	Not measured by study & – waiver - procedures for data collection not in place	Participants' discussion indicated <ul style="list-style-type: none"> • children and families opportunities to be involved in inclusive community and school activities increased • children's opportunities to engage in activities previously restricted & to interact with peers increased.

Table 19 – continued

Quality Assurance Areas and Related Study Results

QA Areas	Study Results	
	Quantitative Results	Qualitative Results
Outcomes Changes in adaptive behavior(s) and role status as consequences of the service	<ul style="list-style-type: none"> • Analysis of change in VABS IIR Adaptive Behavior Composite Scores – Mean scores remained consistent for 1st & 2nd year annual re-evaluation. • The five children whose scores met criteria for inclusion for analysis from group of 11 children assessed for a 3rd year of services (6 children scores indicated scoring errors). The mean of these 5 children's standard scores showed almost a 10-point increase (62.94 – 71.80). • Performance data on children's individual goals not obtained 	Participants discussion indicated <ul style="list-style-type: none"> • increased interaction and social skills • improved language development

Note. QA= Quality Assurance, Autism Specialist, IIS Intensive Individual Support Provider
 VABS II R = Vineland Adaptive Behavior Scales II R. KS SRS = Kansas Department of Social and Rehabilitation Services

Convergent data results revealing KAW implementation concerns and strengths.

Quantitative and qualitative data supported significant concerns with the availability of the services of the intensive individual support (IIS) providers. However, these data also converged to identify an appreciation for the effectiveness of the Autism Specialist role.

Concerns associated with the intensive individual support provider services. The KAW's IIS services are provided by individuals who are charged with actually implementing the strategies to address most of a child's individual behavior plan and plan of care (IBP/POC) goals. The KAW allows for a child to receive 25 hours of IIS services per week. As noted in Chapter 2, this decision was based on considerable research that indicates that from 15 (minimum) to 30

hours a week of intensive behavior analytic intervention is most effective in producing long-term improvements in the functional capacity of young children (Anderson et al., 1987; Howard et al., 2005; Clark et al., 2006; Lovaas, 1987; Lovaas & Smith, 2003; Sallows & Graupner, 2005; Smith et al., 2000). An inspection of the quality assurance areas addressed in Table 18 reveal that inputs, processes, reactions of the participants, and organizational effectiveness each identify concerns or problems associated with the role of the intensive individual support provider.

Problems in finding qualified intensive individual support providers and obtaining the full 25 hours of per week allotted by the waiver for the in-home and community based services of the intensive individual support providers emerged as a major concern of the parents and professionals who participated in the qualitative component of this study. The quantitative data analyses also support this concern. The overall mean of intensive individual support hours provided across the six KAW regions was 7 hours and 13 minutes, which is disturbingly low. The mean range was from 0 hours to 21 hours and 26 minutes with a standard deviation of 5.81. Table 20 displays the means and standard deviations of the weekly hours provided for the intensive individual support service within each of the six regions of the state.

Table 20

Weekly Hours of KAW IIS Services Provided Per Region: 1/30/08 - 11/30/10

Region	Children Served	Weekly Hours ^a	Weekly Hours
		M	SD
West	4	5.86	5.32
Northeast	12	8.10	5.94
South Central	5	9.55	8.87
Wichita	15	5.49	4.62
Southeast	1	3.99	0.00
KC Metro	16	7.87	5.88

Note: KAW =Kansas Autism Waiver; IIS = Intensive Individual Support

^aEach child is allotted 25 hours of IIS services per week.

An inspection of table 20 indicates that the means weekly hours of intensive individual support services fell well below the allotted number of 25 hours per week in each of the six regions. This type of analysis can also be characterized as analysis of dosage or exposure which is recommended as part of the assessment of implementation fidelity and involves assessing the amount of intervention that is delivered to participants, such as the duration and frequency of sessions (Dane & Schneider, 1998; Dusenbury et al., 2003; Knoche et al., 2010; O'Donnell, 2008). These results suggest a significant problem with implementation fidelity in the provision of the intended dosage of intervention.

The comments of the participants in the qualitative components of this study indicated that they believed the rural areas of the waiver experienced more difficulty in accessing sufficient IIS provider services. Rural regions did seem to experience more difficulty than the

urban regions in initially locating IIS providers. However, table 20 shows that IIS services were very limited across all of the regions during the first three years of the waiver and are likely due to a combination of the many barriers to finding and keeping IIS providers that were identified and discussed extensively by the participants in the qualitative component of this study. Barriers that adversely impacted the availability of IIS providers across the state included the: (a) requirements and responsibilities of this position in comparison with the position's hourly pay rate, (c) the lack of travel reimbursement, (c) the extensive and unreimbursed waiver training requirements and (d) the intrinsic limits for job advancement associated with this position.

The issues and needs associated with the concerns related to the insufficiency of the intensive individual supports service hours provided by the KAW and the importance of this service are beginning to emerge in the literature related to the waiver programs. Concern with the availability of sufficient HCBS workers was addressed in a report that identified the key issues associated with the HCBS waiver programs developed by the Kaiser Commission on the Medicaid and the Uninsured (2009). The report, issued in 2009, was based on a working group discussion among Medicaid experts who examined waiver data collected from programs in 2007 and indicated that while more than one million formal caregivers provided paid services in the home in 2007, there are continued shortages of HCBS workers. Hence, the report included a recommendation for giving greater attention to workforce development.

A study conducted by Mandell et al., (2012) sought to determine whether the increased provision of community-based services is associated with decreased psychiatric hospitalizations among children with autism spectrum disorders (ASDs). The results indicated that the increased use of respite and home/community aide services was associated with an 8% decrease in the risk of psychiatric hospitalizations for the study cohort and these researchers conclude that there is a

significant need to expand community-based service options of respite and in-home services.

Interestingly, Mandell et al. also identified that there was not a corresponding decrease in relation to the utilization of therapeutic services, indicating in-home supports were separated from the therapeutic services. This is very different than the KAW, which considers the intensive individual supports service to be the source of primary intervention.

Effectiveness of the role of the autism specialist (AS). During the qualitative component of this study, parents voiced their appreciation of the autism specialists and placed a high value on their services. Parents viewed the autism specialists as having the necessary expertise to ensure that their child's program and services were on target and indicated that their role as team leaders was essential to team collaboration. They reported that the autism specialists ensured that parents were involved in the team and in setting priorities.

The quantitative results lend credibility to the value placed on the role of the autism specialist. Table 12 in Chapter 4 displays comparative information on the allotted hours of KAW services and the service hours actually used and reveals that the autism specialist was the only service for which the mean number of monthly and weekly hours used was greater than the number of hours allotted for the service. Specifically, the KAW provided 4.16 hours per month for the autism specialist, whereas a mean of 4.38 monthly hours were actually used for this service across the state regions. Table 11 in Chapter 2 shows that the range of service hours provided by the Autism specialist across the state regions ranged from 0 to 12.2 with a standard deviation of 2.6. It should also be recalled that the AS service is the only service type that allows additional hours upon request.

The report of the Kaiser Commission on the Medicaid and the Uninsured (2009) also has relevance to this study's findings concerning the role of the autism specialists. Specifically the

report offered the conclusion that maintaining case management service, as part of the broader Medicaid benefits package, is an essential component to expanding access to HCBS.

Divergent data results associated with child outcomes. The quantitative and qualitative data present conflicting data related to child outcomes when one considers the results associated with the Vineland Adaptive Behavior Scale II (VABSII) (Sparrow, Cicchetti, & Balla, 2005, 2006, 2008) and the participants reports of child outcomes. It is important to note that the KAW procedures call for criterion-referenced skill based assessments and the implementation of individual data collection procedures to assess performance and progress on individual child goals. However, the results of these data are not systematically collected and reviewed by the waiver administration, unless there has been a request for an additional year of waiver services. Thus, while waiver participants did indicate that the child teams collected these types of data, they were not accessible for meaningful analyses in this study. Thus, the only quantitative child outcome data collected by this study pertained to the results of the participating children's Adaptive Behavior Composite Standard Scores standard scores obtained on the VABSII.

For a number of reasons, the VABSII data did not provide clear evidence of consistent child outcomes. The qualitative results yielded a number of concerns with the VABSII that offer insight into the some of the quantitative results. Thus, there was convergence between the quantitative and qualitative data in relation to the VABSII.

In contrast to the results associated with the VABSII, the qualitative data did not yield any reports of concerns with the lack of child progress, and, in fact, captured parents' and professionals' enthusiastic reports of positive child behavior changes that improved child and family quality of life. Hence, the child outcomes on the VABS II are discussed first and are

then followed by a discussion of the qualitative results associated with participants' reports of child outcomes.

Vineland Adaptive Behavior Scale II outcomes. All children are assessed with the survey form of the Vineland Adaptive Behavior Scales II (VABSII) (Sparrow, Cicchetti, & Balla, 2005, 2006, 2008) as part of the eligibility determination. If a child is determined to be eligible, this assessment is administered annually thereafter. This discussion of the VABS II results addresses the results of this study's quantitative data, followed by a discussion of the results of this study's quantitative data, and concludes with a brief discussion drawn from the literature that also offers insight in to the Vineland based results obtained in this study.

Quantitative results pertaining to the VABSII. Table 15 in Chapter 4 shows that the means of the Adaptive Behavior Standard Scores obtained on the VABSII were fairly consistent among the initial evaluation, the first annual re-evaluation, and the second annual re-evaluations ($M = 60.11$, $n = 57$ children; $M = 60.39$, $n = 46$ children; and $M = 62.94$, $n = 33$ children respectively) as were their respective standard deviations (9.60, 8.394 and 11.24). The mean of the standard scores for the third annual re-evaluation represents the largest and substantial overall positive increase in the yearly mean of the standard scores (i.e. $M = 71.80$ and $SD = 14.06$). However, this mean represents the scores of only 5 children. This gain is consistent with research that show that significant gains are most likely to be achieved with treatments of longer duration of 2 or more years (Green, 1996, Ramey & Ramey, 1998). However, interpretation of these data is difficult given the small number of children associated with this mean and the fact that the 6 children scores that were eliminated from the analysis were all between 2 and 3 standard deviations below their previous evaluation scores.

As noted in Chapter 2, of the 25 children eligible for the third annual reevaluation, only 11 children were assessed and the other 14 children either exited the KAW early or did not request an additional year of service and therefore, were unfortunately not assessed. And, of the 11 children who children did receive the third annual reevaluation only 5 of these children's standard scores met criteria to remain in the data pool. While gains indicated by the third year reevaluation mean score ($M= 71.80$, $SD=14.06$) in Table 15 align with literature that indicates that early intensive intervention that extends for more than two results in a substantial increase in positive outcomes (Green, 1996; Ramey & Ramey, 1998), the small number of child scores, the large standard deviation and the exclusion of the other participants make the interpretation of these data difficult.

The individual scores dropped from the study's analyses are displayed in Table 16 in Chapter 4. Removal from the data pool for the analysis of children's Adaptive Behavior Standard Scores occurred for 4 children in the first annual reevaluation, 5 children in the second annual reevaluation and 6 children in the third annual reevaluation. Removal of scores occurred when they fell outside the range of expected scores for two primary reasons. If a child's standard score dropped to 20, or if a child's standard score represented a drop of more than one standard deviation in single year, it was removed from the analysis. A standard score of 20 is significantly below the expected range for children participating in the KAW and would indicate that a child with an obtained standard score of 20 had lost almost all of their functional capacity, which, in fact, did not occur. A drop of a standard deviation or greater within one year illustrates an issue with the scoring, especially in the cases when the follow-up scores show that many of these children regained these losses. Explanations for these problematic scores include the possibility of errors in the administration, reporting or the scoring of the assessment or may

represent an attempt to report about the child and/or score in such a manner that a child could remain in the waiver.

Table 17 in Chapter 4 displays the direction of the standard deviation changes (i.e. positive or negative) in the Vineland II Adaptive Behavior Composite Standard Scores of the children participating in the KAW. An inspection of Table 17 shows that slightly more than 50% of the children made gains in their composite standard score for the first two annual assessment intervals. Five of the 11 children made gains in the composite standard score for the third annual assessment interval. The results of the percent of positive changes reported in Table 17 seem aligned with literature that indicates that early intensive intervention results in positive outcomes in approximately 50% of young children with autism diagnoses (Lovaas, 1987; McEachin et al., 1993; Sallows, & Graupner, 2005). The fact that 6 of the 11 children who were assessed for the third year annual reevaluation dropped two or three standard deviations (i.e. 3 dropped two standard deviations and 3 dropped three standard deviations) supports the concern that in some cases there may have been some attempt to either report or score a child's performance to ensure another year in the waiver was assured.

Qualitative results pertaining to the VABSII. Participants in the qualitative component of this study raised concerns about the validity of the reported Vineland scores in general and also made comments that provided some insight into the occurrence of the scores that were dropped from the quantitative analysis. Most of the concerns that were shared by parents addressed their difficulty with understanding how to respond to the assessment questions. The concerns shared by the professional participants reflected doubt about the adequacy of the parents' understanding of their child and/or of the assessment process. And, several of the professional participants

indicated that they had concerns that a parent might answer inaccurately to ensure initial eligibility or underreport their child's performance in order to maintain continued eligibility.

Relevant VABS II research and resources. Research indicates that the VABS II standard scores collected and recorded annually by the KAW quality management specialist should include other score forms in order to improve the validity of analyses of child performance and outcomes. Studies that have used Vineland standard scores have generally reported results that indicate that with age children with autism show a decline in adaptive behavior (Carter et al., 1998; Fisch, Simensen, & Schroer, 2002). Conversely, studies that use Vineland age-equivalent scores demonstrate that children with autism make gains in their adaptive skills, although the gains are a slower rate than peers with typical development (Charman, Howlin, Berry, & Prince, 2004; Schatz and Hamdan-Allen, 1995).

Williams et al. (2006) conducted a study related to evaluating the impact of risperidone on adaptive behavior in children with autistic disorder who have serious behavior problem while also examining different methods of scoring the Vineland Adaptive Behavior Scales to measure the change. These researchers found the VABS II was sensitive in measuring change and were able to report an average gain of average of 7.8 age-equivalent months in the area of socialization, a >6% improvement beyond what would be expected. And, although this research found that VABS II raw scores, age-equivalents, and special norm percentile scores all showed significant increases in adaptive behavior in the areas of communication, daily living skills, and socialization ($p < .01$), it was concluded that Vineland age-equivalent scores appeared to be most useful in assessing change with treatment over time. Williams and his colleagues explained that while standard scores based on national norms or on autism-specific norms may be the easiest to interpret for baseline characterization, the process of standardization reduces variability due to

the floor effects that occur for individuals who function at the lower levels of this assessment. Thus, they concluded that the Vineland standard scores are likely to underestimate improvement.

The need to change the form used to conduct the annual VABS II reevaluations may also be of relevance to the assessment procedures employed by the KAW. The *Survey Interview Form* of the Vineland was consistently used for the initial and annual reevaluations, whereas the VABS II publisher (i.e. NCS Pearson Inc.) recommends that the Parent/Caregiver Rating Form be used for reassessment purposes.

Specifically, the publisher's web site states that:

[The] *Parent/Caregiver Rating Form* covers the same content as the Survey Interview [Form], but uses a rating scale format . . . and is also a valuable tool for progress monitoring. Use the Survey Interview Form on the initial assessment and track progress by using the *Parent/Caregiver Rating Form*. (Retrieved from <http://psychcorp.pearsonassessments.com/HAIWEB/Cultures/enus/Productdetail.htm?Pid=Vineland-II>).

The VABS II publisher's web site also includes information about two other resources of potential relevance to the KAW. The *Teacher Rating Form* contains the same domains as the Survey Forms but covers content that a teacher would observe in a childcare, preschool, or other classroom setting. The *Vineland-II Survey Forms ASSIST* software is also available to assist with scoring the VABS II and can be used with both the *Survey Interview Form* and the *Parent/Caregiver Rating Form* to calculate derived scores. (Retrieved from <http://psychcorp.pearsonassessments.com/HAIWEB/Cultures/enus/Productdetail.htm?Pid=Vineland-II>).

A change from the *Survey Interview Form* to the *Parent/Caregiver Rating Form* for the KAW annual reevaluations may enhance the waiver's access to useful and specific assessment of child progress. Additionally, the *Teacher Rating Form* might be useful to the KAW as a means of assessing the impact of the KAW intervention on the children's adaptive behavior in childcare settings, preschools or elementary schools. Finally, the use of the available *Survey Forms ASSIST™* software might prove helpful in reducing possible scoring errors.

In conclusion, among the key issues identified by the Kaiser Commission (2009) was the increased need to use standardized tools and better information sharing regarding outcomes to increase performance. Consideration of changes to the Vineland Adaptive Behavior Scale – II administration process need to occur in relation the possible use of *Parent/Caregiver Rating Form*, the implementation of improved procedures for ensuring accurate scoring, and the collection of age equivalent scores as well as standard scores. Finally, the power of the VABS II score to continue or deny waiver services for a child also needs to be considered in terms of its impact on the validity of the child scores.

Perceptions of positive child outcomes. The participant's perceptions of positive child outcomes were revealed by the qualitative data collected in this study and are discussed first. Other research that employed quantitative measures and is useful in providing insight into the perceptions of participants associated with child outcomes is discussed next and the relationship of two other studies to the results of this study are considered.

KAW study qualitative results. Despite the many problems that were revealed by the quantitative analysis of the VABS II scores and the administration and reporting problems associated with the VABS II that emerged from the qualitative data, no concerns about child outcomes emerged from the qualitative components of this study. Almost every parent and

provider who participated in the interviews and focus groups enthusiastically discussed the positive changes in their own children or in the children with whom they worked. Very specific accounts of behavior change were shared, as were stories about the improved quality of life gained by both families and children due to their increased access to community settings and opportunities to engage in social interactions.

The possibility that this study's qualitative participants might have believed that an evaluation of the waiver could affect its future funding is an important consideration. Hence, they might have felt confidence in voicing needs for more services, the need for improvements in services or the identification of barriers to needed services. However, these participants may not have felt comfortable about voicing a child's lack of improvement or decrease in a child's level of functioning, as this type of information might contribute to a view of the waiver as ineffective and a subsequent loss of funding.

Related outcome research. A study conducted by Eskow and colleagues (2011) assessed the impact of the services provided through the Maryland Autism Waiver on families' perceived quality of life. This was assessed by a comparison of the responses to the Beach Center Family Quality of Life (FQoL) Scale (Poston et al., 2003) of families receiving waiver services in Maryland with the responses of families on the state's waiver's waiting list. The researchers noted that both groups reported lower satisfaction with their family quality of life than findings from similar studies that included families of young children with less severe disabilities (Summers et al., 2007; Wang et al., 2006). However, the families of children with autism who received waiver services reported a higher family quality of life than those not receiving services through the waiver.

Some of the variables assessed on the FQoL Scale reflect the types of activities and

relationships reported by parents and professionals in the qualitative component of this study as they talked about the waiver's contribution to positive outcomes for the children and families. Interestingly, at the time of the FQoL study (Eskow et al., 2011) the services provided through the Maryland Autism Waiver were fairly similar to the KAW services and included: environmental access/modification; intensive individual support services; therapeutic integration; residential habilitation; family training; respite care; and supported employment. Unlike the KAW, the Maryland waiver served children from early childhood through adolescence, which accounts for the supported employment service.

When one considers the results of the present study in relation to the Eskow et al. (2011) and Mandell et al. (2012) studies, the impact of in-home support services emerges as a common factor. The positive outcomes reported by the present study's participants were each related to a positive change in specific types of challenging behavior that posed significant and ongoing management dilemmas and resulted in family and child isolation. It is plausible that the perception of positive child outcomes and improved quality of life reported by the qualitative participants in this study were related to their access to in-home providers that provided intensive individual support service (despite the fact that the actual availability of IIS providers was significantly under the allotted levels). The considerable emphasis the participants placed on the importance of the IIS providers and barriers to accessing IIS provider services indicates the significance of the value placed on this KAW service component.

The impact of the behavior frequently exhibited by children with ASD on family stress levels was noted in the Mandell et al. (2012) study. Their finding that the availability of respite and in home services was related to a decrease in the number of psychiatric hospitalization for children with ASD was discussed and the possibility that the improved coping abilities of

families who were able to obtain respite and in-home care services was noted.

Research that indicates that having a child with autism places a considerable burden on families and is linked to increased parental stress, depression, and isolation was offered as the reason the FQoL scores of the families receiving the autism waiver services remained lower than FQoL scores on similar studies of families of young children with less severe disabilities in the Eskow, Pineles, and Summers (2011) study of the Maryland Autism Waiver. The impacts of specific waiver service variables were not addressed or related to the finding that the families of children with autism receiving Maryland waiver services had higher FQoL scores than the families of children with autism not receiving waiver services. However, it is interesting that the Maryland waiver also provides intensive individual support and respite care services. In summary, while not a data based find, the results of this study in combination with two other recent studies seem to point to the importance of providing in-home support services to achieve positive child outcomes and meaningful address the needs of parents/caregiver of children with autism.

KAW implementation strengths and concerns revealed by a single research method.

Findings of relevance to the quality assurance analysis of the implementation of the KAW were addressed by only one of the research methods (i.e. quantitative or qualitative) employed by this study. The first is the finding is the underuse of the majority of the KAW services, which is related to the quality assurance factors of input and compliance. The second finding addresses the participants' perceptions and satisfaction with the KAW services and outcomes and is addressed by the quality assurance area for the assessment of the reactions of the participants.

Underuse of a majority of KAW services. Table 12 in Chapter 5 compares the allotted (i.e. maximum number of allowed service hours) average monthly and weekly hours of each of

the service types with the mean of KAW monthly and weekly service hours that were actually provided during the first 35 months of the implementation. An inspection of this table reveals that with the exception of the Autism Specialist services, the provided hours of every service (i.e. Intensive Individual Support; Family Adjustment Counseling; Respite Care; and Parent Support and Training) falls well below the number of hours that are allotted to that service in the waiver. Table 13 in Chapter 4 confirms that this issue is consistent across the state regions. Interestingly, the only concern expressed with the availability of services that emerged in the qualitative component of this study concerned the limited access to sufficient service hours from the IIS providers. Thus, insight into why the other services are underused is not available. It is possible that some of the barriers associated with access to the IIS providers are similar. For example, it may also be difficult to find and maintain respite care providers or counseling services. Or it is possible that these services are not as needed or perceived to be as important to the participants as the other services. The cause of the service underuse needs to be determined and addressed. It is unfortunate that the survey of all the participants (i.e. parents/caregivers and professionals) associated with the KAW planned for this study failed. Different procedures for ensuring its success should be identified and waiver administrative personnel should administer a satisfaction survey on a yearly basis.

Limited measurement of the reactions of participants. Perceptions of the KAW participants in the qualitative components of the study were the means of measuring the reactions of participants that has been identified as a major component of quality assurance (PCMR, 1999) and included as one of the major categories in Table 18. As noted previously, a survey was planned and attempted as part of this study, but failed to do extremely poor participant response rates. While the investigator created the survey, the dissemination of the survey was conducted

through the Kansas Social Rehabilitation Office. Procedures that ensure a better return rate and the annual distribution of a consumer satisfaction survey are essential to a full evaluation of the KAW. Finally, there were a number of services associated with the KAW for which the insight that could have been provided in a survey of parents, providers and professionals associated with the KAW would have contributed to the results of the present study

Data needed for a complete quality assurance analysis. It should be recalled that Hartman (1998) defines quality assurance as, “ The systematic management and assessment procedures adopted to ensure achievement of specified quality or improved quality, and to enable key stakeholders to have confidence in the management of quality and the outcomes achieved” (p. 346). While the results of a number of analyses employed in this study consider the key components of a quality assurance, missing information and types of data and analyses needed for a complete assessment of quality assurance are revealed in Table 19. These include the absence of any measurement of the impact of the KAW and the absence of results that provide reports of individual child progress or criterion based assessment that measure change skills within specific domains. Additionally, no domain scores from the VABS-II were obtained. An investigation directed to the impact of the waiver on the parents/caregivers and children’s quality of life would be useful. While this study tapped into some aspects of quality of life through the qualitative components, a more systematic set of direct observational as well as targeted assessment instruments and interview would be of considerable value in determining the impact and outcomes of this waiver.

Limitations of the Study

Existing data sets that were obtained from the state agency responsible for collecting the data were used for the quantitative analyses. This was cost-effective and necessary in order to

access certain types of data and to ensure the confidentiality of the data. However, this also limited the analyses that could be conducted.

The researchers were also constrained by the state agency's need to manage all initial contacts with participants such as the invitation to participate in the failed survey, which prevented the researcher from trying additional methods of obtaining participation. Additionally, other surveys were being conducted either concurrently to or just preceding the dissemination of the KAW survey.

The limited response rate to the requests for qualitative participants may have impacted the ability to generalize the study results reported in relation to the qualitative component of this study. Those that did not choose to participate may hold different perspectives and have different experiences with the waiver than those who did participate. Additionally, while an attempt was made to ensure that the qualitative participants represent each of the various stakeholder groups, there was not equal representation from each of the states service regions.

Concerns were raised in the discussion of the results about the validity of the scores on the Vineland Adaptive Behavior Scale - II and research that indicated that other forms of the VABS-II than the standard scores available to the researcher may have provided more accurate, less confusing results.

Recommendations for Future Research

In a recently published study concerning a comparison of family quality of life between Maryland Autism Waiver parent/caregiver recipients of the waiver and those on the waiver waiting list, Eskow, Pineles, and Summer (2011) stated that they had located only two published articles related to the Medicaid waiver and autism and found no empirical studies at all about the outcomes of autism waivers. Hence, there is a great need for additional research that identifies

policies and procedures that are essential to the effective delivery of the HCBS autism waiver programs and that offer a robust measurement of the waiver outcomes in relation to improved child functioning and improved child and family quality of life as well as consider the overall societal impact of the waiver.

Continued and routine evaluation of the KAW needs to occur that includes the repeated measurement of many of the variables that were included in this study and also expands the analysis to more carefully address child progress and outcomes, parent/caregiver satisfaction and procedures that ensure an improved implementation of procedures guided by the targeted evidence based practices. Components of a quality assurance analysis should guide the evaluation and the fidelity of implementation must be carefully documented.

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Appendix A

Consent Form for Parent Participation in Interview Process

Approved by the Human Subjects Committee University of Kansas, Lawrence Campus (HSCL). Approval expires one year from 2/22/2010. HSCL #18311
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INFORMED CONSENT STATEMENT: Autism Waiver Parent Interviews

Assessing the Quality of Implementation & the Effectiveness of the Autism Waiver in Kansas

INTRODUCTION

The School of Education at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. Refusal to participate will have no effect on your services. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with the University of Kansas or with any of your services.

PURPOSE OF THE STUDY

The purpose of this project is to learn about the perceptions of key stakeholders in Kansas Autism Waiver Program concerning the various components of the program and the overall quality and satisfaction with the service delivery provided to families of children with autism through the waiver. Stakeholder information can provide critical information necessary for the program to maintain, drop, revise and/ or create procedures to assist the program in striving for the highest quality possible. It is anticipated that the interview process will provide increased insight and understanding about perceptions that were indicated on the previously administered Autism Waiver Survey about the Kansas Autism Waiver

PROCEDURES

You have been asked to participate in an individual interview about your experiences as a parent or parents whose child is receiving services via the Kansas Autism Waiver. An interview will last approximately 30 minutes to an hour in a place of convenience to you and will consist of questions about your experiences with the assessment process, the treatment process, your impressions regarding the evidence regarding effectiveness, problem solving mechanisms, barriers you have encountered, and changes you would recommend given your experiences. We are asking your permission to audiotape these sessions. Tapes will only be heard by the researchers and a paid transcriptionist. At no time will any of your identifying information be disclosed. You will be provided with a copy of the transcript so that you can indicate any changes you wish to make to your interview to best reflect your perceptions.

DATA SECURITY

The signed consent forms will be kept in a locked file cabinet in a locked office. Pseudonyms will be used on any data collection sheet that is used (i.e., for data collected on the child and parent). Audiotapes will be downloaded and kept on a strong password-protected computer with a firewall protection. All the

interviews will be audiotaped. The audiotapes will only be reviewed by the researcher or project staff for transcription. When the comments are transcribed if you include your child's name in any comments, that name will be replaced with a pseudonym. The files will be immediately downloaded onto the research computer after the session and deleted from the recorder. The University laptop computer will be kept in a locked office at the University or with the researcher at all times. The audio files will be deleted/destroyed after 5 years.

We propose to submit the results of this study collected during conference presentations and in publications. Neither you nor the child will be identified, and information in the interview is confidential since another name (pseudonym) will be used. Information regarding diagnosis will only be used if it comes directly from you (the participant). No private health information about you or your child will be obtained from the agency you are affiliated with.

The program director, Pamela Keller has sent you this consent form as well as a brief description of the study and the researcher's contact information if you are interested. Feel free to contact the researcher if you are interested in this study.

RISKS

Talking about your experiences regarding services for your child with an autism spectrum disorder can be emotionally taxing. We intentionally chose the individual opened ended interview process to ensure your comfort and privacy while offering us your perceptions and insight into the processes you have experienced via Autism Waiver program. Additionally, we will also provide you with information on local support and advocacy groups for parents of children with autism spectrum disorders.

BENEFITS

Parent can provide invaluable, unique information to state-level administrators. Participation in this study will benefit other families of children with ASDs by allowing us to make recommendations based on parent reports about areas in which service delivery, coordination and quality assurance needs greater development.

PAYMENT TO PARTICIPANTS

Participants will receive \$50 for participating in the interview process and an additional \$25 if they complete the entire interview.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any way with the information collected about you or with the research findings from this study. To report narrative information from focus groups, researchers will use a pseudonym instead of your name. At no time will your identifying information be shared in any way. Your quotes may be shared, but they will be linked only to a pseudonym or a descriptor such as "a parent from Western Kansas."

Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: Nan Perrin, 801 S. Brentwood, Olathe, KS 66061. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email mdenning@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form

_____	_____
Type/Print Participant's Name	Date

Participant's Signature	

Researcher Contact Information

Barbara J. Thompson, Ph.D.	Nanette Perrin
Department of Special Education	801 S. Brentwood
University of Kansas	Olathe, KS 66061
Joseph R. Pearson Hall -Rm. 521	785-865-5520 ext. 320
1122 West Campus Road	785-218-9347 cell

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Appendix B

Consent Form for Provider Participation in Focus Groups and Interviews

Approved by the Human Subjects Committee University of Kansas, Lawrence Campus (HSCL) on 2/4/2011. Approval expires one year from 2/22/2011. HSCL# 18311

INFORMED CONSENT STATEMENT: Autism Waiver Provider Interviews

Assessing the Quality of Implementation & Effectiveness of the Autism Waiver in Kansas

INTRODUCTION

The School of Education at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. Refusal to participate will have no effect on your services. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with the University of Kansas or with any of your services.

PURPOSE OF THE STUDY

The purpose of the project is to gather opinions and perspectives about the autism waiver services from the individuals who have directly experienced these services. Stakeholder information can provide critical information necessary for the program to maintain, drop, revise and/ or create procedures to assist the program in striving for the highest quality possible. This information will be used to provide the state with recommendations about how to improve the autism waiver and what types of strategies can be best used to evaluate the autism waiver on an ongoing basis.

PROCEDURES

You have been asked to participate in a individual interview on the experiences of key stakeholders who are participating in the Kansas Autism Waiver. Interviews will last approximately 1-2 hours and will consist of questions about your experience with the assessment process, the treatment process, your impressions regarding the evidence regarding effectiveness, problem solving mechanisms, barriers you have encountered, and changes you would recommend given your experiences. We are asking your permission to audiotape these sessions. Tapes will only be heard by the researchers and a paid transcriptionist. At no time will any of your identifying information be disclosed. You are also being asked to complete a brief questionnaire prior to the focus group.

DATA SECURITY

The signed consent forms will be kept in a locked file cabinet in a locked office. Pseudonyms will be used on any data collection sheet that is used (i.e., for data collected on the child and parent). Audiotapes/Videotapes will be downloaded and kept on a strong password-protected computer with a firewall protection. All the interviews will be audiotaped or videotaped. The audiotapes/videotapes will only be reviewed by the researcher or project staff for transcription. When the comments are transcribed if you include your child's name in any comments, that name will be replaced with a pseudonym. The files will be immediately downloaded onto the research computer after the session and

deleted from the recorder. The University laptop computer will be kept in a locked office at the University or with the researcher at all times. The audio files will be deleted/destroyed after 5 years.

We propose to submit the results of this study collected during conference presentations and in publications. Neither you nor the child will be identified, and information in the interview is confidential since another name (pseudonym) will be used. Information regarding diagnosis will only be used if it comes directly from you (the participant). No private health information about you or your child will be obtained from the agency you are affiliated with.

The program director, Pamela Keller has sent you this consent form as well as a brief description of the study and the researcher's contact information if you are interested. Feel free to contact the researcher if you are interested in this study.

RISKS

Talking about your experiences regarding services in which you have partially participated can be emotionally taxing.

BENEFITS

Stakeholder focus groups can provide invaluable, unique information to state-level administrators. Participation in this study will benefit families of children with ASDs by allowing us to make recommendations based on reports about areas in which service delivery, coordination and quality assurance needs greater development.

PAYMENT TO PARTICIPANTS

Participants will receive \$50 upfront for agreeing to participate and an additional \$25 upon completion of the interview. Personal identifying information will be collected from the participant solely for submission to the contracting agency for payment. This information will in no way be linked to your interview results. But simply provide the mechanism for a payment to be made to you for your participation.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any way with the information collected about you or with the research findings from this study. To report narrative information from focus groups, researchers will use a pseudonym instead of your name. At no time will your identifying information be shared in any way. Your quotes may be shared, but they will be linked only to a pseudonym or a descriptor such as "a provider from Western Kansas."

Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: Nan Perrin, 801 S. Brentwood, Olathe, KS 66061. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email mdenning@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

Type/Print Participant's Name

Date

Participant's Signature

Researcher Contact Information

Barbara J. Thompson, Ph.D.

Nanette Perrin

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Appendix F

Consent Form for

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INFORMED CONSENT STATEMENT: Autism Waiver Focus Groups

Assessing the Quality of Implementation & Effectiveness of the Autism Waiver in Kansas

INTRODUCTION

The School of Education at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with the University of Kansas.

PURPOSE OF THE STUDY

The purpose of the project is to gather opinions and perspectives about the autism waiver services from the individuals who have directly experienced these services. Stakeholder information can provide critical information necessary for the program to maintain, drop, revise and/ or create procedures to assist the program in striving for the highest quality possible. This information will be used to provide the state with recommendations about how to improve the autism waiver and what types of strategies can be best used to evaluate the autism waiver on an ongoing basis.

PROCEDURES

You have been asked to participate in a focus group on the experiences of key stakeholders who are participating in the Kansas Autism Waiver. Focus groups will last approximately 1-2 hours and will consist of questions about your experience with the assessment process, the treatment process, your impressions regarding the evidence regarding effectiveness, problem solving mechanisms, barriers you have encountered, and changes you would recommend given your experiences. We are asking your permission to audiotape and/or videotape these sessions. Tapes will only be seen and heard by the researchers and a paid transcriptionist. At no time will any of your identifying information be disclosed. You are also being asked to complete a brief questionnaire prior to the focus group.

RISKS

Talking about your experiences regarding services in which you have partially participated can be emotionally taxing. We intentionally chose the focus group format to provide support within the context of a group of colleagues who are seeking to better understand and improve current services. Our hope is that the format will attenuate risks to participants by bringing together those with common experiences.

BENEFITS

Stakeholder focus groups can provide invaluable, unique information to state-level administrators. Participation in this study will benefit families of children with ASDs by allowing us to make recommendations based on reports about areas in which service delivery, coordination and quality assurance needs greater development.

PAYMENT TO PARTICIPANTS

Participants will not receive remuneration for their participation in this study.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any way with the information collected about you or with the research findings from this study. To report narrative information from focus groups, researchers will use a pseudonym instead of your name. At no time will your identifying information be shared in any way. Your quotes may be shared, but they will be linked only to a pseudonym or a descriptor such as “a parent from Western Kansas.”

Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: Nan Perrin, 2113 Delaware, Lawrence, KS 66045. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email mdenning@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

Type/Print Participant's Name

Date

Participant's Signature

Researcher Contact Information

Barbara J. Thompson, Ph.D.

Nanette Perrin

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Appendix D

Semi Structured Interview Questions: Parent

Semi Structured Interview Questions: Parent

Each interview will begin with an overview, reminding participants that they do not have to answer any questions that they do not want to. And also asking permission to audiotape.

Functional Eligibility Assessment (Note: The functional eligibility screening is the Vineland Adaptive Behavior Scales, Second Edition (Vineland-II))

Tell me about the process.

What was most frustrating part of the eligibility assessment?

What was the most beneficial part of the assessment?

What do you wish had been different in the beginning?

How accurately did you think the assessment identified the strengths and needs of the child?

Assessment and Program Planning

How soon after choosing an autism specialist did your program planning begin?

What was your experience during the program planning process?

What was most helpful in the beginning?

What was most frustrating?

How accurately did you think the assessment identified your child and family strengths and needs?

Do you feel the assessment accurately targets your family and child needs?

What do you wish had been different in the beginning?

What went well during this process?

Services/Interventions

What kinds of services/programs/interventions has your child received?

How easy was it to identify providers?

Have you found providers for each service you indicated needing on your plan of care?

What was the process of provider enrollment like?

Where did you go to access these services/programs/interventions?

How effective have the services been for your child?

In which areas is there evidence of skill acquisition?

What evidence is available on the effectiveness?

Is the evidence utilized to make changes if necessary to the services?

Best Practices and Changes to the System

What has helped most?

What have been biggest obstacles you've faced?

If you could change three things about the way Autism/Asperger treatment has been provided, what would you change?

If you could make one recommendation to the state, what would it be?

If you had a concern about an area who would you contact?

Are you aware of the steps if you are confused/concerned about any of the services?

Are there ways to assess evidence for the effectiveness that are not currently being utilized?

Appendix E

Focus Group and Provider Semi-structured Interview Questions

Focus Group and Provider Semi-Structured Interview Questions

Each interview will begin with an overview, reminding participants that they do not have to answer any questions that they do not want to. And also asking permission to audiotape or videotape the interview.

Functional Eligibility Assessment (Note: The functional eligibility screening is the Vineland Adaptive Behavior Scales, Second Edition (Vineland-II))

Did you participate in the Functional Eligibility Assessment?

What was your impression regarding the process of the Functional Eligibility Assessment?

How accurately did you think the assessment identified the strengths and needs of the child?

Assessment

Did you participate in the program planning and assessment?

What are your perceptions of the process?

What was the most helpful in the process?

What was the most frustrating part of the process?

How accurately did you think the assessment identified the strengths and needs of the child and family?

Do you have the strategies and supports necessary to provide the services outlined in the Individual Behavioral Program/Plan?

Services/Interventions

What was the process of provider enrollment like?

Where did you go to access these services/programs/interventions?

How effective have the services been for the child?

In which areas is there evidence of skill acquisition?

What evidence is available on the effectiveness of the services?

Is the evidence utilized to make changes if necessary to the services?

Best Practices and Changes to the System

What has helped most?

What have been biggest obstacles you've faced?

If you could change three things about the way Autism/Asperger treatment has been provided, what would you change?

If you could make one recommendation to the state, what would it be?

If you had a concern about an area who would you contact?

Are you aware of the steps if you are confused/concerned about any of the services?

Are there ways to assess evidence for the effectiveness that are not currently being utilized?

Appendix F

Telephone Focus Group Questions

Telephone Focus Group Guiding Questions

1. Tell me about your impressions of the eligibility determination process.
 - a. Both what you observed and what families/providers told you.
2. Their direct experience with an Autism specialist and secondly, what parents have said to them about their own interaction with the Autism specialist.
 - a. If during your reviews you worked with any autism specialist. Tell me how that worked.
 - b. What was family's overall impression of their work with the autism specialist.
3. They are supposed to check if the criterion referenced skill based assessment process has influenced the service plan.
 - a. Has the service plan developed in accordance with state approved policies and procedures.
 - b. Has parent input been obvious
 - c. What were the goals like and Was there data being collected?
 - d. What data on progress was shared?
 - e. When looking at the plans did you identify gaps or areas of improvement?
4. What did parents tell you were the most beneficial part of the individual behavior program planning process?
 - a. Did they identify things that needed change?
 - b. What were similarities or differences that you saw across reviews?
5. Services/interventions
 - a. Tell me how you feel the services have affected the children and families through the waiver.
 - b. What challenges gaps did families tell you about related to services
 - c. How satisfied were families?
6. Tell me about the changes you have seen in the child or the changes that were reported?
 - a. What type of evidence of changes did you see in the children you interviewed?
 - b. If the changes were measured, tell a little about that.
7. From experience, both what you observed and what families and providers told you:
 - a. What has been the most helpful?
 - b. What have been the biggest obstacles?
 - c. If you could make three recommendations to the state, what would they be?